

THE ROLE OF THE HEALTHY PARENT IN ADOLESCENTS' ADJUSTMENT TO  
PARENTAL PHYSICAL ILLNESS

By

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## TABLE OF CONTENTS

	<u>page</u>
ACKNOWLEDGMENTS.....	ii
ABSTRACT.....	v
 CHAPTER	
1 INTRODUCTION.....	1
2 REVIEW OF LITERATURE.....	4
Prevalence of Chronic Illness in Parent Populations .....	4
Adolescents and Stress.....	5
Parental Physical Illness and Child/Adolescent Functioning.....	8
Models of Parental Physical Illness and Child Functioning.....	22
Critique of Current Models.....	28
Factors Associated with Child/Adolescent Functioning.....	30
Child Factors.....	30
Parent Factors.....	35
Illness Factors.....	39
Family Factors.....	40
3... AIMS AND STUDY JUSTIFICATIONS... ..	49
Purpose of the Study.....	49
Hypotheses.....	49
Hypotheses Related to Levels of Adolescent Adjustment.....	49
Hypotheses Related to Parent-Adolescent Communication.....	49
Hypotheses Related to Ill vs. Healthy Parent Reports of Adolescent Adjustment.....	50
4 METHOD.....	51
Participants.....	51
Ill Parents.....	51
Healthy Parents.....	53
Adolescents.....	53
Family Demographics.....	53

Procedure.....	54
Measures.....	55
Demographics.....	55
Perceptions of Illness Questionnaire.....	56
Reynolds Adolescent Depression Scale (RADs).....	56
Children's Manifest Anxiety Scale- Revised (RCMAS).....	57
Impact of Event Scale (IES).....	57
Parent-Adolescent Communication Scale (PACS).....	60
Child Behavior Checklist (CBCL).....	62
5 RESULTS.....	64
Preliminary Analyses.....	64
Primary Analyses.....	67
Hypothesis 1: Adolescent Adjustment to Parental Physical Illness.....	67
Hypothesis 2: Effects of Same Sex Ill Parents.....	72
Hypothesis 3: Adolescent Perceptions of Ill vs. Healthy Parent Communication.....	73
Hypothesis 4: Relationship Between Parent-Adolescent Communication and Adjustment.....	75
Hypothesis 5: Effects of the Presence of Parental Positive Relationships..	79
Hypothesis 6: Ill vs. Healthy Parent Reports of Adolescent Adjustment...	80
6 DISCUSSION.....	84
Discussion of Major Findings.....	84
Hypothesis 1: Adolescent Adjustment to Parental Physical Illness.....	84
Hypothesis 2: Effects of Same Sex Ill Parents.....	92
Hypothesis 3: Adolescent Perceptions of Ill vs. Healthy Parent Communication.....	93
Hypothesis 4: Relationship Between Parent-Adolescent Communication and Adjustment.....	94
Hypothesis 5: Effects of the Presence of Parental Positive Relationships..	98
Hypothesis 6: Ill vs. Healthy Parent Reports of Adolescent Adjustment...	99
Summary of Findings.....	101
Contributions and Weaknesses of the Present Study.....	102
APPENDIX.....	110
REFERENCES.....	112
BIOGRAPHICAL SKETCH.....	121

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The objective of the present study was to examine the relationship between parent-adolescent communication and psychological functioning among adolescents who live with parents who have chronic physical health conditions. Three members of each family (healthy parents, ill parents, and adolescents) completed questionnaires. Results indicated that nearly one-third of the sample reported clinically meaningful levels of stress-response symptoms related to their parent's illness. Adolescent communication with the healthy parent was significantly associated with symptoms of anxiety but not depression. However, communication with the ill parent was not associated with adolescent adjustment. Finally, evidence from the present study does not provide adequate support for the hypothesis that biases exist in the reporting of adolescent behavior problems by ill parents in comparison to healthy parents. These findings suggest that adolescents with severely ill parents may experience symptoms of anxiety not typically assessed in this population. Furthermore, the relationship with the healthy

parent may serve an important and unique function for these adolescents and may be a useful target for clinical intervention.

## CHAPTER 1 INTRODUCTION

Obesity, substance abuse, depression, and chronic physical health problems are commonly experienced by adults of parenting age. Inasmuch as a parental health problem may affect numerous aspects of family life, exposure to this stressor may have negative effects on millions of children. However, “despite the high incidence and clinical relevance of parental health problems, the impact of such problems on children and families has not been well described” (Drotar, 1994, p. 526). The amount of scientific knowledge available varies depending on the health problem. While there is a fair amount of research on the impact of alcoholism on children’s development, relatively little information exists related to parental chronic physical illness as it affects children.

The effects of parental physical illness on children and adolescents continue to grow in importance. Thousands of people in parenting age are diagnosed with chronic conditions each year. Advances in medicine have increased the life expectancy for many individuals with chronic illnesses and have allowed them to continue their lives at home rather than in health care facilities. These factors, coupled with great strides in fertility treatments for adults who once may not have been able to become parents, have increased the number of children living with a parent who has a chronic health condition.

While such medical advances are positive, data suggest that children of chronically ill parents may exhibit more symptoms of psychological distress than

children of healthy parents. Investigators have explored several variables to determine their relationships with outcomes for children in these families. One variable that has been related to poorer outcomes is age. Specifically, findings suggest that adolescents may be at greater risk than younger children for experiencing psychological distress when a parent is ill. Drawing from findings in the general adolescent stress literature, researchers have begun to explore the role of parent-child relationships on children's psychological functioning in these families, generally finding an association between less conflicted parent-adolescent relationships and better adolescent psychological functioning. However, it seems likely that in families in which one parent is ill and one is healthy, adolescents may maintain different relationships with these two parents. While investigators have developed models of child functioning considering both parents separately, no study has simultaneously considered the influence of both parent-adolescent relationships in predicting children's adjustment.

The purpose of the present study was to further delineate key variables in predicting adjustment for a population that appears to be at risk for psychological distress, adolescents of physically ill parents. Specifically, the focus was to investigate the simultaneous influence of the ill parent-adolescent relationship and healthy parent-adolescent relationship on adolescent adjustment. It was hypothesized that the healthy parent relationship would be more strongly related to adolescent adjustment than the ill parent-adolescent relationship. Understanding the relative importance of this relationship is a contribution to the literature that has direct clinical implications.

The current document begins with a description of the prevalence of parental illness, followed by a review of studies examining the impact of stressors during



adolescence. Next, literature on the impact of parental physical illness on children's functioning is reviewed, including theoretical models describing mechanisms by which this effect may be exerted. An examination of studies investigating these variables follows. Finally, a study conducted to test the stated hypotheses is described, with findings from the data reported and implications of those data discussed.

## CHAPTER 2 REVIEW OF LITERATURE

### Prevalence of Chronic Illness in Parent Populations

Parental illness can represent a highly salient stressor for children and adolescents. A disease and its treatment can be an emotionally intense experience for both the patient and family members and can be characterized by a variety of emotions including fear, anxiety, anger, confusion, and depression. Illness can result in extensive changes throughout the family and give rise to a great deal of uncertainty regarding such factors as disease course, heritability, and outcome. Children of ill parents are often faced with the potential for both short-term losses, such as parental hospitalizations and disrupted routines, and long-term losses, including parental death and ongoing family disruption (Leedham & Meyerowitz, 1999). Rait and Lederberg (1989), commenting on families of cancer patients specifically, referred to family members as “second-order patients” as a result of the stressors to which they are exposed. Yet despite recognition of these experiences, children of ill parents have received little attention in the research literature.

Statistics describing the prevalence of chronic illness in adults in their child-rearing years are impressive. Six of the ten leading causes of death for adults age 25 to 44 are chronic conditions, including malignant neoplasms, heart disease, and HIV. In 1997, these resulted in over 59,000 deaths in this parenting age group (Hoyert, Kochanek, & Murphy, 1999). In addition, there are thousands of other adults who live with chronic

diseases affecting the heart, liver, kidney, lung, and pancreas. For instance, the United Network for Organ Sharing (UNOS) reported that as of January 17, 2000, the number of individuals between the ages of 18 and 49 on the waiting list for solid organ transplants was over 35,000 (<http://www.unos.org>), and it is estimated that over half of patients evaluated for transplantation are not listed for various medical and psychological reasons. In addition, from 1994 to 1998 transplant centers reported performing 56,523 solid organ transplants on patients in this age range. In short, significant numbers of families are affected by health conditions serious enough to warrant organ transplantation. Millions more are affected by other conditions that are debilitating but not necessarily life-threatening. For instance, for every 1000 adults in the United States between the ages of 18 to 44, there are 51.6 people with asthma, 46.9 with arthritis, 11.4 with diabetes, and 5.8 with epilepsy (Benson & Marano, 1998).

#### Adolescents and Stress

The effects of stress in adults have been the focus of scientific study for many years. In comparison, research on the effects of stressful life circumstances in adolescents began only recently (Compas, Slavin, Wagner, & Vannatta, 1986). A life events approach, focusing on significant changes in an individual's life, has provided the conceptual framework for much of the work in this area. Empirical research has suggested that stressful life events are significantly related to child and adolescent adjustment in several areas, including internalizing behaviors, externalizing behaviors, and school performance (Johnson, 1986). This finding has been demonstrated in both cross-sectional research (e.g., Forehand, Middleton, & Long, 1987) and prospective studies (e.g., Siegel & Brown, 1988).

Studies indicate that as the number of concurrent stressors in an adolescent's life increases, adolescent functioning decreases. This relationship has been demonstrated across several domains, including academic functioning (Forehand et al., 1991; Forehand et al., 1987; Simmons, Burgeson, Carlton-Ford & Blyth, 1987), internalizing symptoms (Compas et al., 1986; Forehand et al., 1991; Siegel & Brown, 1988), somatic complaints (Compas et al., 1986; Siegel & Brown, 1988), self-esteem (Simmons et al., 1987), externalizing problems (Forehand et al., 1991), and participation in extracurricular activities (Simmons et al., 1987). These findings have been demonstrated with both familial stressors, such as divorce and parent-adolescent conflict (Forehand et al., 1991; Forehand, Middleton, & Long, 1987), and normal developmental events, such as dating and transition to junior high school (Simmons et al., 1987). These data generally show linear relationships. However, some data suggest that one or two stressors have relatively few effects on adolescents, but three or more stressful life events are associated with a sharp increase in problems in areas of adjustment noted above (Forehand et al., 1987; Simmons et al., 1987). There is also some evidence to suggest that the negative impact of family stressors on adolescents may not be fully seen until young adulthood (Forehand, Biggar, & Kotchick, 1998).

Simmons and colleagues (1987) proposed that the stress of life events can be eased for the adolescent if he or she has "arenas of comfort" (p. 1232) where the individual can withdraw to regroup. The parent-adolescent relationship may be one such arena for adolescents experiencing significant stressors. However, the proposition by Simmons et al. (1987) implies that adolescent satisfaction with the "arena," here, the parent-adolescent relationship, is important. Indeed, adolescent satisfaction with the

social support, not the number of support mechanisms available, has been related to fewer psychological symptoms (Compas et al., 1986). Research has also specifically supported the notion that parent-adolescent relationships with less conflict are associated with better adjustment for adolescents under stress (Forehand et al., 1987; Forehand et al., 1991; Wierson, Forehand, Fauber, & McCombs, 1989). For example, Neighbors, Forehand, and McVicar (1993) found that a less conflictual relationship with their mothers distinguished adolescents rated as resilient to stress from those who were not. In somewhat conflicting findings, Forehand et al. (1991) found that adolescent perceptions of the father-adolescent relationship exerted a main effect on externalizing problems regardless of the number of family stressors experienced. The same was true for adolescent perceptions of the mother-adolescent relationship and its relationship with the adolescent's grade point average. However, an interaction effect was noted for adolescent internalizing problems. As the number of stressors in the adolescent's life increased, a positive father-adolescent relationship was associated with fewer internalizing symptoms. Forehand and colleagues, citing research by Montemayor and Hanson (1985), suggested that the mother-adolescent relationship is typically more conflictual than the father-adolescent relationship. Therefore, adolescents may rely on fathers more than mothers in times of stress. Regardless of the source of this finding, it supports the notion that a good parental relationship can have a stress-buffering effect for an adolescent.

However, one flaw of many of the studies examining adolescent stress is that stressors are equated. Unlike adult research on life stress, which uses "life change units" to weight the presumed impact of various stressors (Johnson, 1986), adolescent stress

research has not accounted for differing effects of adverse life events. For example, in the study by Simmons and colleagues (1987), parental death and entering puberty were each counted as “one stressor” despite vast differences in the impact of these two events. Because of this, research on the effects of different types of stressors remains unclear.

Some work exploring specific adolescent life events, such as parental divorce, has been conducted. The divorce literature has reported findings similar to those of the general adolescent stress research. For example, in a study of male adolescents, Wiersen et al. (1989) reported that adolescents who felt they had good relationships with both divorced parents were rated by teachers as exhibiting better academic performance and fewer conduct problems than did adolescents who described poor relationships with both divorced parents. The researchers detected no significant differences between adolescents from divorced families and intact families as long as the adolescent perceived good relationships with both parents.

Collectively, these data highlight two important ideas for the current investigation. First, adolescents appear to be at risk for negative consequences when experiencing several stressful life events. Second, parent-adolescent relationships may have a critical role in buffering these negative effects.

#### Parental Physical Illness and Child/Adolescent Functioning

Despite the staggering number of parents who have chronic health conditions, our knowledge of the impact of parental illness on children’s psychological adjustment remains limited (Armistead, Klein, & Forehand, 1995; Drotar, 1994). Nevertheless, recent reviews of the existing literature concluded that parental physical illness appears to be associated with problems in children’s functioning (Armistead et al., 1995; Worsham,



Compas, & Ey, 1997), although the extent of these problems remains somewhat controversial (Kahle & Jones, 1999). Several hypotheses have been offered regarding the relationship between parental illness and children's adjustment problems. Wellisch et al. (1992), for instance, suggested that parental illness can draw attention away from children, as well as drain emotional and material resources. Moreover, threats to security in the parent-child relationship may be felt by children and adolescents through increased parental unavailability, changes in daily routines, or fear of parental death (Armsden & Lewis, 1993). Concern for the parent's well being may also cause adjustment difficulties for children with a chronically ill parent. Various possibilities have been proposed, and explanations for these problems are likely to be influenced by the child's stage of development. Regardless of the mechanism by which parental illness may put children at risk, studies suggest that children of ill parents are more likely to exhibit higher levels of psychological symptoms than children of healthy parents (see Table 1).

In a study comparing children of mothers who had either chronic pain, diabetes, or no illness, self-reports of depression, but not anxiety, were significantly higher for children of mothers with chronic pain than those with no illness (Dura & Beck, 1988). Scores for children of mothers with diabetes fell between those of the other two groups, but were not significantly different from either of them. A nonsignificant trend emerged toward higher levels of parent-reported total behavior problems for children of parents with chronic pain or diabetes when compared to children of parents with no illness. However, since each group in the study contained only seven subjects, the sample size may have hindered detection of effects. In addition, for parent reports only total behavior problem scores were reported; therefore it is not possible to determine whether these

Table 1

Summary of Findings from Empirical Studies of Children of Parents with Chronic Physical Illness

Authors	Parent/illness	n	Age range	Main findings
Armistead et al. (1997)	Fathers/hemophilia and HIV	67	3-18	A more positive parent-child relationship was related to less child depression and externalizing problems and better school performance.
Biggar et al. (1998)*	Mothers/HIV	85	6-11	Children of HIV-positive mothers reported more depressive symptoms than children of HIV-negative mothers. Maternal depressive symptoms were not related to children's depression. Children's depression scores did not differ based on whether the mother was symptomatic.
Chun et al. (1993)	Mothers and fathers/chronic pain	35	6-16	Teachers, but not parents, reported that children of chronic pain patients had more behavior problems and less social competence. Parent functional disability, but not the patient's gender, depressive symptoms, or marital satisfaction, predicted parent-reported child behavior problems.
Compas et al. (1994)	Mothers and fathers/cancer	110	6-32	Disease characteristics were generally not related to anxiety/depression or stress-response symptoms for adolescents. Perceived seriousness and perceived stressfulness were associated with stress-response symptoms. Self-reports of anxiety/depression were significantly higher for adolescents than for younger children. Adolescent girls with ill mothers reported the most difficulties.
Compas et al. (1996)	Mothers and fathers/cancer	134	6-32	Adolescents reported using more emotion-focused coping than younger children. Emotion-focused coping was related to symptoms of adolescent anxiety/depression.
Dorsey et al. (1999)	Mothers/HIV	100	6-11	Presence of additional adults in the home was not predictive of better child psychosocial functioning.



Table 1. Continued

Authors	Parent/ illness	<u>n</u>	Age range	Main findings
Dura & Beck (1988)*	Mothers/ chronic pain, diabetes	14	7-13	Self-reports of depression, but not anxiety, were significantly higher for children of mothers with chronic pain than those of healthy moms. Scores for children with diabetes were between the two groups. A nonsignificant trend toward greater parent-reported behavior problems emerged for children whose parents had chronic pain or diabetes.
Forehand et al. (1997)	Fathers/ hemophilia (some with HIV)	137	3-18	Parent-reported internalizing symptoms differed between children whose parents had hemophilia only and those whose parents were also HIV-positive but asymptomatic. More conflict was reported in the mother-child relationship when the father's HIV status was positive, and worse still when he was HIV symptomatic. Hemophilia severity was not associated with parent reports of child functioning.
Forehand et al. (1998)*	Mothers/ HIV	87	6-11	Self-reported depression and aggression were significantly higher for children of HIV-infected mothers. Parent-reported social competence and cognitive competence were significantly lower for children of infected mothers. Several mean scores for children of infected mothers were in the borderline clinical or clinical range.
Forsyth et al. (1996)*	Mothers/ HIV	26	6-16	Significant differences were observed between children of infected vs. uninfected mothers on parent-reported withdrawal, anxiety/depression, social competence, and attention problems. Significant differences were observed between children of symptomatic and asymptomatic HIV-positive mothers on self-reported anxiety and parent-reported anxiety/depression.

Table 1. Continued

Authors	Parent/illness	<u>n</u>	Age range	Main findings
Grant & Compas (1995)	Mothers and fathers/cancer	55	11-18	Girls whose mothers were ill reported more family responsibilities, which accounted for the interaction between sex of ill parent and sex of adolescent in predicting anxiety/depression.
Hirsch, Moos, & Reischl (1985)*	"Parents"/rheumatoid arthritis	16	12-18	Adolescents of parents with arthritis participated in fewer school activities and reported lower self-esteem than controls. For many variables there were also no significant differences between adolescents of parents with arthritis and adolescents of parents with depression.
Howes et al. (1994)	Mothers/breast cancer	32	4-18	Mothers who reported more psychological distress rated their children as having more emotional and behavior problems.
Kotchick, Forehand et al. (1997)*	Mothers/HIV	86	6-11	HIV-infected mothers reported more parent-child conflict and less monitoring of their children than uninfected mothers. These two variables were important predictors of child-reported internalizing and externalizing problems and parent-reported social competence.
Kotchick, Summers et al. (1997)	Fathers/hemophilia (some with HIV)	53	7-18	Perceived parental social support was significantly predictive of parent-reported externalizing problems, self-reported depression, and academic competence. In addition, child perceptions of parental support significantly predicted parent-reported internalizing symptoms and self-reported depression in families where parents reported high physical and psychological impact of illness.
Lewis et al. (1993)	Mothers/breast cancer	40	6-12	The peer relations of children whose mothers had breast cancer were correlated with the quantity and quality of exchanges between the healthy parent and the child, but were not correlated with ill parent-child interactions.

Table 1. Continued

Authors	Parent/illness	n	Age range	Main findings
Mikail & von Baeyer (1990)*	Unstated/migraine headache	24	9-17	Children of chronic headache sufferers exhibited more problems in general adjustment, internalizing problems, somatic complaints, externalizing problems, and social skills than children of healthy controls. Mean scores were within normal limits.
Peters & Esses (1985)	Mothers and fathers/multiple sclerosis	33	12-18	Compared to controls, adolescents from families with a parent with MS rated their families higher on conflict and lower on cohesion.
Rodrigue & Houck (2001)*	Mothers and fathers/various illnesses	33	11-15	Presence of a chronic health condition in fathers, but not mothers, was related to more behavior problems in adolescents. Nonsignificant trend toward interaction between sex of ill parent and sex of adolescent in predicting behavior problems.
Rotherham-Borus & Stein (1999)	Mothers and fathers/AIDS	239	11-19	Parental ill health was related to adolescent self-reports of internalizing symptoms and somatic complaints.
Rotherham-Borus, Stein, & Lin (2001)	Mother and fathers/HIV	211	11-18	Better adolescent adjustment predicted by lower parental distress and physical symptoms in a two-year follow-up.
Siegel et al. (1992)	Mothers and fathers/terminal cancer	42	7-16	Target children had significantly higher levels of self-reported depression and anxiety and more parent-reported internalizing and externalizing behavior problems than controls. They also had lower self-esteem and lower parent-reported social competence.
Steele, Forehand, & Armistead (1997)	Fathers/hemophilia (some with HIV)	69	3-18	Healthy parent-child relationship problems accounted for nearly twice as much variance in children's adjustment as ill parent-child relationship problems, although both were significantly associated with child internalizing problems.
Steele, Tripp, et al. (1997)	Fathers/hemophilia (some with HIV)	65	3-18	The child's uncertainty about the father's illness predicted children's self-reports of both anxiety and depression.

Table 1. Continued

Authors	Parent/illness	<u>n</u>	Age range	Main findings
Stein et al. (1999)	Mothers and fathers/ AIDS	183	11-19	Taking on adult roles was associated with having an ill mother, being female, and greater parent drug use. Follow-up 3-9 months later indicated that taking on adult roles was associated with more behavior problems.
Wellisch et al. (1991)*	Mothers/ breast cancer	30	18-65	No differences found on measures of long-term psychological adjustment. Differences were noted on measures of sexual functioning.
Wellisch et al. (1992)	Mothers/ breast cancer	60	18-65	Retrospective accounts of discomfort regarding their mother's illness were greater for women who were adolescents at the time than for women who were adults.
Zahlis (2001)	Mothers/ breast cancer	16	11-18	Retrospective accounts indicated that children had many worries during their mother's illness and made considerable effort to make sense of the experience.

Note. \* = Sample size listed for between subjects studies reflects only number of subjects in the target group (i.e., control children are not included).

problems were of an internalizing or externalizing nature. The authors also do not state which parent or parents rated their child, which may be relevant to interpreting findings. Finally, the clinical meaningfulness of the findings is questionable since all mean scores fell in the nonclinical range.

Chun, Turner, and Romano (1993), using a somewhat larger sample, examined behavior problems and social competence of children whose parents were either healthy or living with chronic pain. Combined parent ratings did not indicate significant differences on either construct. However, a strength of this study was its use of teacher ratings, which showed a pattern of results that differed from parent reports. Teachers rated children of pain patients as having significantly more behavior problems and being

significantly less socially competent than children of control families, although mean scores were within nonclinical limits. The authors suggest that behavior problems in these children may be manifested more often outside the home or that they may be more noticeable by outside observers. Like Dura and Beck (1988), these authors reported total behavior problems, thus leaving the nature of the problems in this sample unclear.

Another methodological weakness of this study is the fact that parents with more than one child were allowed to select which child they rated for the study. Parents may have chosen children they perceived as having few problems, thus leading to a conservative estimate of problems in the sample. The lack of self-report measures also weakens the conclusions that can be drawn.

In another study, children of parents with chronic headaches were reported by their ill parent to exhibit significantly more internalizing behaviors, externalizing behaviors, somatic complaints, and social skills deficits than children whose parents were healthy (Mikail & von Baeyer, 1990). However, mean scores were in the nonclinical range, and no significant group differences on anxiety or withdrawal were reported.

Hirsch, Moos, and Reischl (1985) compared adolescents of parents with arthritis to those of parents with depression and those without a health condition. Adolescents of patients with arthritis reported significantly lower self-esteem and less participation in school activities. Scores on measures of psychological symptoms for adolescents of the parents with arthritis were consistently between those of teens with depressed parents and those of healthy parents and not significantly different from those of children of depressed parents. The study also examined the impact of life events on psychological symptomatology. Their results revealed that children of ill parents reported significantly



more negative events in the past twelve months than did healthy parents and that both positive and negative life events were associated with increases in symptoms for adolescents whose parents had arthritis. This was not true for children of healthy parents. This may indicate that any changes in the lives of these young people can negatively disrupt their well being.

Studies of the adjustment of children with physically ill parents are not limited to the chronic pain literature. Wellisch et al. (1991), in a study of adult daughters of mothers who had breast cancer, found no differences on a variety of psychological dimensions, including depression and somatization, when compared to a matched control group of women. The only differences emerged on measures of sexual satisfaction and frequency of sexual intercourse. However, this study explored the long-term adjustment of individuals with an ill parent and does little to illuminate concurrent adjustment. In addition, the sample consisted entirely of upper class Caucasian women, which may have provided resources that aided in the adjustment of these individuals.

In a separate retrospective study of adult women who had had a parent with cancer, Leedham and Meyerowitz (1999) also found no significant differences on measures of psychological adjustment when compared to matched controls. Qualitatively, the women recalled several ways in which their experiences with their parent's cancer had affected their lives. In addition to negative outcomes such as feeling more fearful of death, these grown children noted positive changes as well, including feeling they were stronger people and appreciating others more. However, they also reported significant disruption in family functioning caused by the disease during the illness and its treatment.

Concurrent reports of children whose parents have terminal cancer have suggested more psychological difficulties when compared to matched controls (Siegel et al., 1992). Children of ill parents, whose prognosis was less than six months survival, reported significantly more depressive symptoms, more anxiety symptoms, and lower self-esteem than community control children. Parent-report measures, completed by the healthy parent, also indicated significantly higher levels of both internalizing and externalizing behavior problems and lower social competence. Average scores on all measures for this sample were in the subclinical range, however, several children reported clinically significant depressive symptoms. Nearly twice as many of the target children (27%) were in the clinical range on self-reported depression. In addition, significantly more target children were in the clinical range for parent-reported externalizing problems, total behavior problems, and social competence problems. Interpreting these findings for purposes of the current investigation is problematic, since it is difficult to disentangle the impact of illness from the impact of the impending death of a parent. However, given that many patients pursuing transplants are given a two-year prognosis for survival without a transplant, the issue of severity can be likened to some degree. Also, participants in this study were predominantly middle to upper class, a problem common to studies in this literature (e.g., Lewis, Hammond, & Woods, 1993; Wellisch et al., 1991).

Families with lower socioeconomic status (SES) have been studied, mostly in describing the adjustment of healthy children whose mothers are HIV-positive. For instance, Forehand et al. (1998) conducted a study of inner city, low SES, African-American children whose mothers were HIV-positive. Only 20% of the children in the

study were aware of their mother's diagnosis. Nonetheless, the investigators found significant differences between children of HIV-positive parents and children of healthy parents on measures of child-reported depression and aggression. Maternal reports of these constructs did not reveal statistically significant differences; average scores for both groups were in the borderline clinical and clinical ranges. However, maternal reports of social competence and cognitive competence indicated significantly less competence for children of infected mothers when compared to uninfected mothers. No measures of anxiety were included in the study. That significant findings for self-report measures were obtained in a sample in which a small number of children were aware of their mother's diagnosis would suggest that circumstances that accompany the disease, not the disease itself, put children at risk for psychological difficulties. However, an important caution should be considered with this study. Although control families were from the same community, matching procedures were limited to the school, age, and gender of the child. The authors note that this omits maternal variables important to this population (e.g., maternal drug use) that may also differentiate these two groups. Also relevant for the current study is the fact that the vast majority of the mothers in this sample were single. Presumably, a healthy parent was not available from whom children might seek support, which may be an additional consideration in the unusually high scores on measures of child maladjustment.

Forsyth et al. (1996) also reported psychological difficulties in this population. While no differences in self-reported anxiety between children of HIV-positive and HIV-negative mothers were revealed, statistically significant differences in anxiety symptoms were observed between children of symptomatic and asymptomatic mothers. In addition,



parents reported more symptoms of anxiety/depression, withdrawal behavior, and attention problems in children of infected mothers compared to uninfected mothers. Parent reports of somatic complaints, externalizing problems, and social problems were not significantly different between the two groups. Although there was only a nonsignificant trend toward greater parent-reported total behavior problems, 52% of the target children was in the clinical range on this construct, whereas 32% of the control group was in this range. No differences were detected between children of symptomatic and asymptomatic mothers on any parent-report measure, except anxiety/depression symptoms. Similar to the Forehand et al. (1998) findings, less than half of the children in the study had been told of their mother's disease.

Biggar et al. (1998), using the same sample as Forehand et al. (1998), and Forsyth et al. (1996) found higher self-reported depression scores for children of infected vs. uninfected women. Average scores in these studies were similar to the findings of Siegel et al. (1992). Also similar to that study, greater numbers of target children than control children were in the clinical range for depression. Thirteen percent and 19% of children with infected mothers were in the clinical range in the Biggar et al. (1998) and Forsyth et al. (1996) studies, respectively, compared with 4% from control groups in each study. This difference was statistically significant in the former study but nonsignificant in the latter.

Studies using between-subjects designs to determine whether the concurrent psychological functioning of children with an ill parent differs from that of children with healthy parents typically note discrepancies. Many children from families with the stressor of an ill parent appear to function relatively well, yet it is clear that some do not.

While scores on measures of psychological functioning for children of ill parents are typically in the nonclinical range of measure norms, they are also often significantly higher than scores of children of healthy parents. In addition, several studies reported that more children with ill parents exhibited clinical levels of psychological symptoms than children of healthy parents (Biggar et al., 1998; Forsyth et al., 1996; Siegel et al., 1992).

While other reviews have concluded that these differences exist mainly in internalizing symptoms (Kotchick, Summers, Forehand, & Steele, 1997; Worsham et al., 1997), the present review highlighted other areas of functioning that may be affected as well. Although results are mixed, several studies reported significantly higher levels of self-reported (Forehand et al., 1998) and parent-reported (Mikail & von Baeyer, 1990; Siegel et al., 1992) externalizing problems. In addition, lower social competence was described in several studies using both teacher (Chun et al., 1993) and parent (Forehand et al., 1998; Mikail & von Baeyer, 1990; Siegel et al., 1992) reports. Nonetheless, internalizing symptoms were often associated with parental physical illness. However, differences in internalizing problems were more uniformly observed in children's self-reports than parent reports. Within children's self-reports, depression revealed consistent differences (Dura & Beck, 1988; Forehand et al., 1998; Forsyth et al., 1996; Siegel et al., 1992), while self-reports of anxiety were less consistent. However, one possibility is that severity of illness may be an important predictor of anxiety reactions. Forsyth et al. (1996) found no differences in anxiety between children of ill and healthy parents; however, differences did emerge between symptomatic and asymptomatic parents. Siegel et al. (1992) studied children of parents with a terminal illness and found

differences on measures of anxiety as well. It may be that as children are provided with more salient cues that their parent's illness is worsening, symptoms of anxiety may be more likely to arise in response. This hypothesis is consistent with conclusions that particular family or illness factors may be related to specific child adjustment domains (Armistead et al., 1995; Steele, Tripp, Kotchick, Summers, & Forehand, 1997). In reference to the present study, it is important to note that the decision to pursue transplantation, radiation, or dialysis may have signified a cue to adolescents that their parent's condition was worsening, thus increasing the possibility of an anxious reaction.

Finally, these findings suggest important considerations of reporter issues. First, the consistent findings of elevated internalizing symptoms in children's self-reports, combined with only mixed findings on parent reports, may suggest that some of the adjustment problems in these children are often covert. If so, these easily could be overlooked in families experiencing more salient stressors, such as parental physical frailty or economic distress. Dorsey, Watts Chance, Forehand, Morse and Morse (1999) have suggested that as a parent's condition worsens, his or her ability to detect their child's difficulties may decline. Indeed, Worsham and colleagues' (1997) review of this literature concluded that evidence for maladjustment is clearer from children's and adolescents' self-reports than from parents' reports. Second, three of the studies reviewed above used ill parents as reporters, one used the healthy parent, one averaged two parents' ratings, and one used unclear methodology. The only study that consistently found more problems on all domains measured was that using the healthy parent as a reporter (Siegel et al., 1992). It may be that healthy parents are in a special position to detect difficulties for children in these families. While this is a very tentative suggestion,

given the limited data and other unique aspects of the study such as the terminal population examined, rarely is the role of the reporter in the family and potential biases from this role discussed when considering results. There is research to suggest that mothers and fathers do not report different numbers of problems (Achenbach, 1991b; Stanger & Lewis, 1993) and that there is no sex of parent by sex of adolescent effect in the number of problems described by parents (Achenbach, Howell, Quay, & Conners, 1991; Stanger & Lewis, 1993). Given that these factors do not appear to have a significant impact on reports, the potential impact of the reporter's health status should be considered.

In summary, these data highlight three important conclusions relevant to the current investigation. First, children and adolescents whose parents have chronic health conditions appear to be at risk for internalizing symptoms. It can be argued that these symptoms may be of greater concern for these young people because other stressors in the family may prevent adults from detecting and/or intervening. Second, anxiety symptoms especially may be relevant when increasing illness severity becomes salient to the child or adolescent. Finally, reporter issues may influence findings, therefore multiple sources of information (e.g., child, ill parent, and healthy parent) are critical to research in this area.

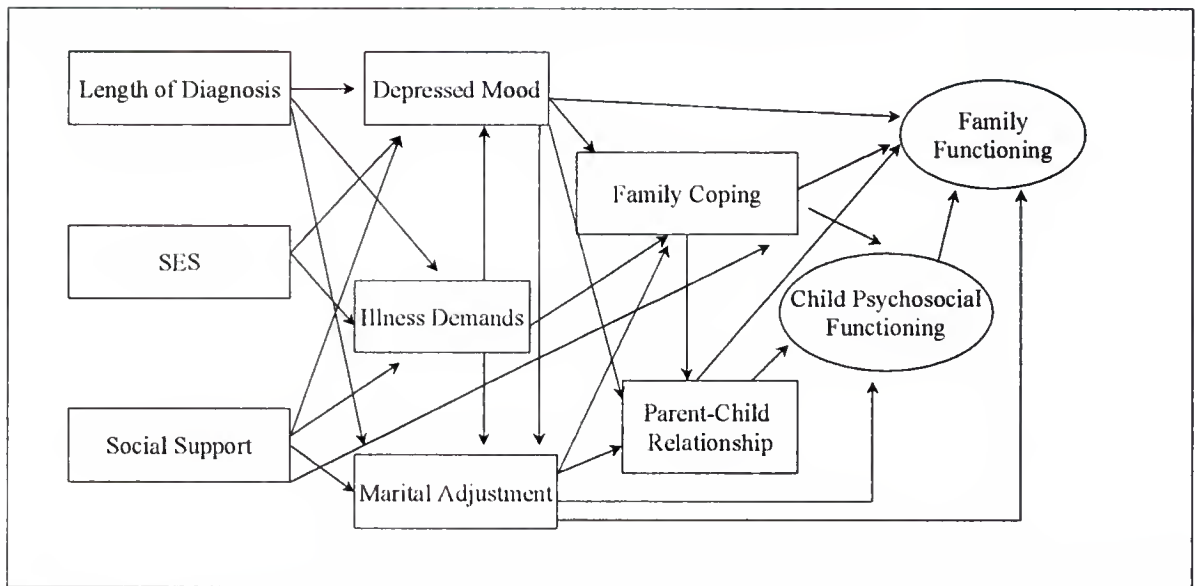
### Models of Parental Physical Illness and Child Functioning

Four models explaining the impact of parental illness on child functioning have been proposed in the literature. Two of these models have been explicitly tested. This section presents these models with critiques specific to each model. In the next section, a broader conceptual critique of the models is presented.

Lewis et al. (1993) developed and tested a model of child and family functioning when the mother has breast cancer (Figure 1). This complex model hypothesized that environmental factors (e.g., socioeconomic status, social support) predicted perceived illness demands, which predicted parental depression, marital adjustment, and family coping. The latter variables were hypothesized to indirectly predict child psychosocial functioning through the parent-child relationship. In addition, marital adjustment and family coping were suggested to directly predict children's adjustment.

This model was tested separately for mothers and fathers, and results for both models were similar. Illness demands and, for mothers only, social support significantly predicted symptoms of depression, which predicted marital adjustment. Lower marital satisfaction predicted, for both parents, poorer family coping and, in the mother model only, poorer parent-child relationships. In the mother (ill parent) model, family coping, but not the parent-child relationship, significantly predicted child psychosocial functioning. In the father (healthy parent) model, the parent-child relationship significantly predicted child adjustment. This suggests that the two parent-child relationships served different functions for the adolescents in this study, such that their interactions with the ill parent had little impact on adjustment, while relationships with the healthy parent were highly correlated with positive functioning.

This study represents the first published conceptual model of children's adjustment to an ill parent. It includes a number of important variables that previously had been unstudied. However, one major criticism of this model is its lack of attention to child variables (e.g., age, sex) as predictors of child functioning, despite evidence suggesting that these variables may have important roles. In addition, child adjustment in



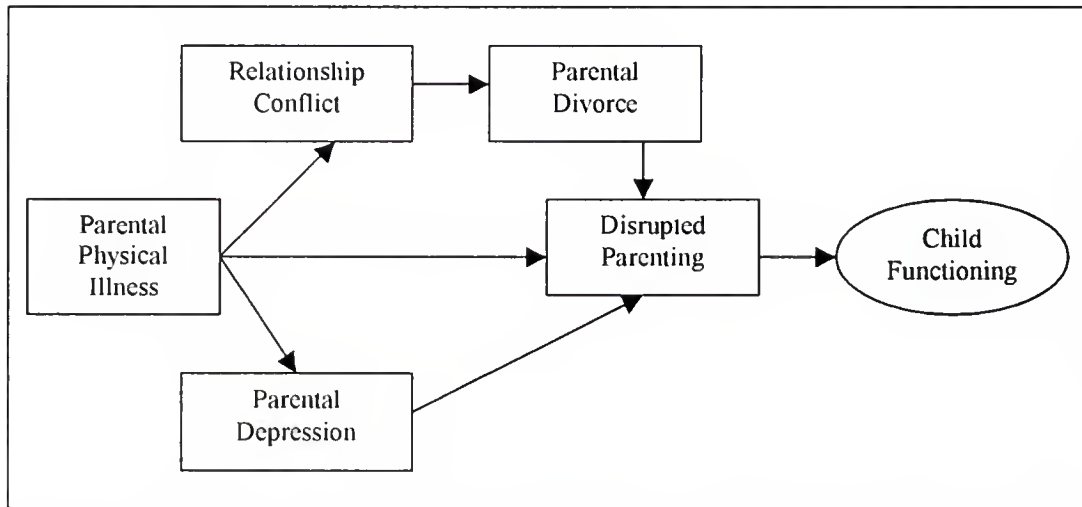
**Figure 1.** Model of how maternal breast cancer influences family functioning proposed by Lewis, Hammond, and Woods (1993).

the study was measured by a single questionnaire subscale, “peer relations,” and the study was limited to preadolescent children. Therefore, the generalizability of conclusions drawn from this rather specific domain of functioning and from this age group is questionable and limits interpretation of the findings.

Based on their review of the research, Armistead et al. (1995) proposed a model of how parental physical illness influences child adjustment (Figure 2). In this model, disrupted parenting is the key mechanism by which parental illness affects child functioning. Parental physical illness is hypothesized directly and indirectly to predict parenting. Indirect mechanisms include increased relationship conflict and greater parental depression, which are also hypothesized to predict parenting disruptions. This model is consistent with some of the research from the general adolescent stress literature (e.g., Ge et al., 1994). While not incorporated into the model, another strength of the authors’ discussion of the proposed model is the issue of reciprocal relationships. The



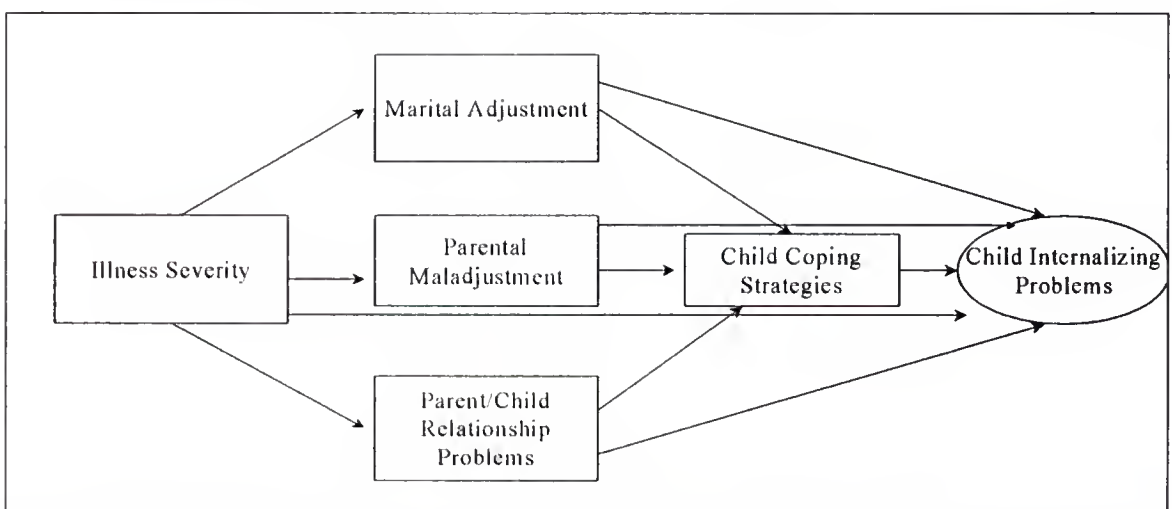
authors note that constructs such as parental depression and relationship conflict may have an impact on the parent's physical health.



**Figure 2.** Model of how parental physical illness influences child functioning proposed by Armistead, Klein, and Forehand (1995).

In what appeared to be a revision of this model, Steele, Forehand, and Armistead (1997) reported empirical findings for a proposed model for predicting child internalizing problems when a parent is chronically ill (Figure 3). This model does not focus on disrupted parenting as the primary mechanism affecting children, but rather maintains that illness severity affects family process variables (i.e., marital conflict, parental maladjustment, and parent-child relationship problems). Family process variables, in turn, have both a direct impact on children's internalizing problems as well as an indirect impact through children's coping strategies. This model was examined separately for mothers and fathers, using families in which the fathers had hemophilia, some of whom were also HIV-positive. Variables in the mother (healthy parent) model accounted for 45% of the variance in children's internalizing symptoms. Significant paths existed from illness severity to maternal depression and from maternal depression to child internalizing problems. The paths from mother-child relationship problems, measured

here by parent-child conflict, to children's avoidant coping and to children's internalizing problems were also significant. Finally, the path from children's avoidant coping to children's internalizing problems was significant. No paths to or from marital adjustment were significantly related to any other factors in the model. Variables in the father (ill parent) model accounted for 41% of the variance in internalizing symptoms of the children in this sample. Significant paths from illness severity to marital adjustment and paternal depression emerged. Paternal depressive symptoms were significant predictors of marital adjustment, father-child relationship problems, and child internalizing problems. As with the mother model, the paths from father-child relationship problems to both children's avoidant coping and to children's internalizing problems were significant, as was the path from children's avoidant coping to children's internalizing problems. Notably, the path from parent-child relationship problems accounted for nearly twice the variance in the mother model as it did in the father model, again suggesting a relatively more important role for the healthy parent-child relationship in predicting children's adjustment.



**Figure 3.** Model of relationships among parental physical illness and child internalizing problems proposed by Steele, Forehand, and Armistead (1997).



Another important conceptual conclusion can be drawn from the results of this study. The authors stress that while illness severity was indirectly related to child internalizing problems, the direct path to child adjustment was not significant. This suggests that it is not the illness itself, but rather the effects it has on the family, that affect child psychological functioning. However, the measurement of the illness severity construct in this study is of concern. First, illness severity was determined by combining diverse objective measures of illness (HIV status, bleeds per year, per cent of clotting factor) and subjective parent ratings of the impact of the illness. Therefore, the roles of objective severity indicators and illness perceptions cannot be teased apart to determine their respective impacts on the model. Second, children's perceptions of their parent's illness severity were not considered in the illness severity construct. Presumably, a child's cognitions about their parent's condition would be useful in examining their adjustment.

A final model from the Forehand research group (Family Health Project Research Group, 1998) has been proposed explicitly for families of mothers with HIV (Figure 4). Because of the nature of HIV and its associated patient demographic characteristics in the sample chosen, this model is significantly different from the other models. Environmental stressors and economic resources are more fully incorporated into this model. Interestingly, the parent-child relationship, which was strongly associated with functioning in the previous study, is not included in this proposal. However, parenting, absent from the previous revision, appears again in this model. Child factors, including coping strategies, self-sufficiency, and knowledge of the illness, are viewed as important predictors.

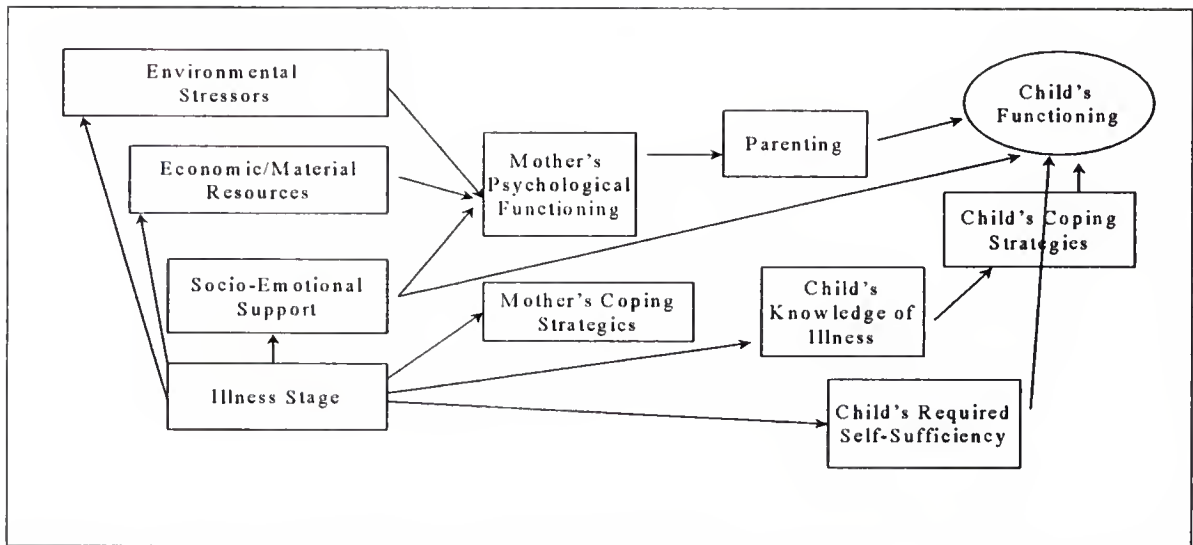


Figure 4. Model of factors associated with how maternal HIV influences child psychosocial functioning proposed by The Family Health Project Research Group (1998).

### Critique of Current Models

These models have provided a framework for research in this area thus far. All of them share a common element in that they are focused on parent and family functioning as the critical predictors of child adjustment. However, the emphasis on illness and child factors varies from model to model. More recent findings have improved our knowledge of child functioning in families of an ill parent, and several limitations of these models should be noted. First, in light of our current knowledge, each model omits variables empirically demonstrated to be correlated with child adjustment. For example, developmental factors, child sex, and patient sex are not included in current models. The first two models by the Forehand group are relatively simplistic; each includes five variables considered to be predictive of child adjustment. The last model omits the parent-child relationship completely and, because of the sample studied, is a single-parent model. While it may be useful in predicting the adjustment of children in families with a

mother who has HIV, this model likely would not generalize to families with other illnesses.

This raises a second concern. With the exception of Armistead et al. (1995), the models proposed have been developed for specific diseases, not illness in general. While specific disease characteristics should not be ignored, the impact of parental illness as a general stressor on the adjustment of children and adolescents has been understudied. Mechanisms common to diseases remain unclear, limiting the generalizability of this research.

Both of the models that have been empirically examined have tested the impact of parents on child adjustment for patients and partners separately. Neither model includes the co-occurring influences of both parents. Given that evidence suggests that the ill and healthy parents may serve different roles in these families, it would appear to be beneficial to include separate pathways in the same model to study relative differences in prediction of adjustment. Simultaneously considering the influences of each parent on the adolescent, as well as on each other, is important and remains unexplored in the current literature.

Finally, the nonrecursive nature of these models is problematic. As previously noted, Armistead et al. (1995) suggested the importance of considering reciprocal relationships when considering the context of the family. For example, they suggest that parental physical illness can influence parental depression, and, in turn, depression can influence physical illness. There are many other relationships in this literature that should be considered reciprocal that are typically not. Child adjustment is viewed as the dependent variable of parental independent variables, such as depression or parent-child

relationships. However, child adjustment easily can be viewed as influencing these parental variables as well, creating vicious cycles for maladjustment. While the methodology of the present study did not allow for empirical tests of this argument, the interpretation of findings should consider the possibility of reciprocal relationships.

The models presented have provided valuable guides for the literature in testing variables believed to be related to child and adolescent adjustment. Studies testing these and other relevant constructs have provided new information about predictors of adjustment in children with ill parents.

#### Factors Associated with Child/Adolescent Functioning

Several factors have been examined as predictors of children's psychological adaptation to parental physical illness. While few variables have been examined with multiple samples, preliminary conclusions can be drawn regarding the relevance of factors potentially affecting child outcomes.

#### Child Factors

Children's psychological adjustment to parental illness has been found to be associated with the child's age. For example, Compas et al. (1994) found that adolescents reported significantly more anxiety/depression symptoms than did young children. Wellisch et al. (1992) found that adults who were adolescents at the time of their mother's breast cancer diagnosis retrospectively reported feeling greater discomfort about involvement with their mother's illness than did women who were over twenty years old. In contrast, some researchers have found no relationship between child age and adjustment to parental illness (e.g., Kotchick, Summers, et al., 1997).

Theoretically, it has been suggested that parental illness may interfere with classical conceptualizations of the adolescent developmental tasks of separation and individuation (Armsden & Lewis, 1993; Wellisch et al., 1992). Armsden and Lewis (1993) suggested that the family's needs for cooperation and cohesiveness may conflict with the adolescent's needs to become more involved in roles outside of the family and to express oneself as an individual. Adolescents with an ill parent may feel drawn back to the family due to the illness, causing distress or self-loathing over these conflicting roles. In a qualitative study of adolescents of terminal cancer patients, Christ, Siegel, and Sperber (1994) reported that typical adolescent themes, such as sibling conflict and complaints regarding parental supervision, seemed accentuated in this population. In addition, their interviews revealed that adolescents in these families often felt divided between achieving developmentally appropriate goals and the need to deal with the practical aspects of having a terminally ill parent. The authors also reported that adolescents were more likely than younger children to describe guilt about developmentally appropriate feelings of anger toward their parent for being ill.

One reason for difficulties in separating from the family may be increasing responsibilities at home. When a parent is ill, adolescents, especially girls, may be more likely than younger children to be called upon to take on new roles in the family (Compas et al., 1994; Grant & Compas, 1995; Stein et al., 1999). Family responsibility stressors, such as chores, have been associated with higher internalizing symptoms in adolescents whose parents have cancer (Grant & Compas, 1995) or AIDS (Stein et al., 1999). Parental role-taking, such as helping with important family decisions, has been associated

with higher externalizing behavior problems in adolescents of parents with AIDS, including sexual activity, substance use, and conduct problems (Stein et al., 1999).

Greater cognitive awareness also may contribute to elevated distress responses in adolescents (Christ et al., 1994; Compas et al., 1994; Worsham et al., 1997). Christ et al. (1994) reported that adolescents in their study appeared to comprehend both the illness and its ramifications better than young children. It may be that a more thorough understanding of the implications for the ill parent and for the family leads to more difficulties for adolescents than for younger children who are unable to process the nuances of the situation. In addition to understanding the immediate impact on one's life, it has been suggested that daughters of mothers with breast cancer may be at risk for adjustment difficulties because of the realization of the possible genetic risk for cancer themselves (Wellisch et al., 1991). However, one empirical test of this hypothesis did not reveal significant differences in depression/anxiety symptoms in adolescent girls whose mothers did vs. did not have sex-linked cancers (Grant & Compas, 1995).

It has also been hypothesized that adolescents may be given more information by adults than young children or asked by adults to provide information about the illness, yet they may lack the necessary coping strategies for handling this information (Compas et al., 1994). This may lead to maladaptive coping strategies. In fact, adolescents of parents with cancer have been found to use more emotion-focused coping than preadolescent children, which has been associated with more avoidance reactions (Compas et al., 1996). This coping strategy was related to more symptoms of anxiety and depression.



Main effects for child sex have not typically been found in studies reporting such analyses (e.g., Chun, et al., 1993; Kotchick, Summers, et al., 1997; Rodrigue & Houck, 2001; Steele, Forehand, & Armistead, 1997). However, differences were detected in a study of adolescents of parents with HIV, in which adolescent boys reported more problem behaviors than girls and girls reported more emotional symptoms than boys (Rotherham-Borus, Stein, & Lin, 2001). While atypical, these findings suggest that boys and girls in this situation may manifest distress in different ways.

While not present in all studies (e.g., Chun et al., 1993), a significant interaction between the sex of the child and the sex of the ill parent has been found in others. Specifically, female adolescents whose mothers had cancer have more symptoms of anxiety and depression than females with ill fathers or males whose mothers or fathers were ill (Compas et al., 1994). Rodrigue and Houck (2001) found a similar, but statistically insignificant, pattern of results for both female and male adolescents. Multiple hypotheses regarding this interaction should be considered. First, there are indications from the general parent-adolescent relationship literature that suggest that differences exist in parent-child dyads. Steinberg (1987) has described these dyads as a continuum of emotional involvement in which mother-daughters are most intense and father-daughter relationships are most flat. It may be that these emotional interactions are exacerbated by parental illness. Second, there is evidence to suggest that female adolescents with ill mothers take on the responsibilities of that parent in the home, adding to their life stress and internalizing symptoms (Grant & Compas, 1995; Stein et al., 1999). Unfortunately, most studies in this area have used single-sex parent populations,

limiting the conclusions that can be drawn regarding the importance of the interaction between these two variables.

In addition to age and sex, children's perceptions of their parent's illness appear to be related to their psychological adjustment. For example, Compas et al. (1994) reported that greater perceived illness severity was associated with higher levels of stress response symptoms (avoidance and intrusive thoughts) in adolescents, but was not related to symptoms of internalizing problems. The perceived stressfulness of the parent's cancer was correlated with both stress response and internalizing symptoms. It is important to note that the methodology used to assess children's perceptions (i.e., single Likert-type ratings) and the timing of the assessment (i.e., near the time of the patient's initial diagnosis) may explain the higher levels of stress response symptoms but no difference for more stable anxiety and depression symptoms. No other studies have explicitly examined the role of children's perceptions of their parent's illness in predicting adjustment, although the perceived ambiguity children experience about their parent's illness may be related to anxiety and depression (Steele, Tripp, et al., 1997). While this finding does not specifically support the notion that perceived illness severity is important to adjustment, it does indicate that children's perceptions of the situation do have an impact on their functioning. While preliminary, these two studies suggest that children's perceptions of their parent's illness should be examined further.

How a child copes with their parent's illness is another factor that may be associated with their adjustment. For instance, Compas et al. (1996) found that adolescents reported more emotion-focused coping and dual-focused coping, coping strategies aimed at controlling both internal reactions and external characteristics of their



parent's cancer. The use of emotion-focused coping among children of ill parents was correlated with more anxiety/depression symptoms and perceptions that the illness was more stressful. Specifically, avoidance strategies were associated with worse disease stage, perceptions of greater seriousness, perceptions of greater stressfulness, and more anxious/depressive symptoms. Avoidant coping strategies were also predictive of child internalizing problems in a study of fathers with hemophilia, some of whom also had HIV (Forehand et al., 1997). The only significant predictor of child avoidant coping in this study was problems in parent-child relationships, suggesting that these relationships may be as important in these families as has been found in the general adolescent stress literature.

#### Parent factors

Researchers (e.g., Kotchick, Forehand, et al., 1997; Lewis et al., 1993) consistently assert that parental physical illness indirectly affects children's adjustment by operating through family variables. Parental adjustment has been associated with outcomes for these children. Numerous studies in the general clinical literature suggest that children of parents with an affective disturbance are at greater risk for psychological problems than children whose parents do not exhibit such disturbances (Beardslee, Versage, & Gladstone, 1998). The same may be true for children of physically ill parents since both patient and healthy parent depressive symptoms have been found to be directly (Steele, Forehand, & Armistead, 1997) and indirectly (Lewis et al., 1993) predictive of child psychosocial functioning. This has been demonstrated longitudinally as well. Structural equation modeling data by Rotherham-Borus, Stein, and Lin (2001) suggested that the emotional distress of parents with HIV is predictive of adolescent emotional

distress two years later, again indicating a relationship between parent and adolescent functioning.

Other measures of the ill parent's adjustment to the illness have demonstrated relationships to child psychological symptomatology as well. Fathers' ratings of their own greater physical and global psychological symptoms significantly predicted combined parent ratings of child internalizing problems as well as children's self-reports of depression (Kotchick, Summers, et al., 1997). Howes, Hoke, Winterbottom, & Delafield (1994) found similar results between the self-reports of psychological adjustment to illness of women with breast cancer and their reports of their children's total psychological symptoms, although the validity of these ratings is of concern given that the ill parent completed both measures. Nonetheless, Howes et al. (1994) suggested that the parents' perceptions of the illness and their reactions to it might influence the way the child interprets the illness. There is some empirical evidence to support this hypothesis in addition to results related to parental depression. For example, Rodrigue and Houck (2001) found that mothers' perceptions of poorer health-related quality of life were associated with more adolescent behavior problems, while the objective presence of a chronic condition was not. However, this relationship was stronger and more consistent in parent reports of behavior problems than adolescent reports of their own behavioral difficulties.

Similarly, in a study of children of parents with chronic pain, patient psychological symptoms were significantly correlated with parent reports of child anxiety, somatic complaints, and general adjustment (Mikail & von Baeyer, 1990). Chun et al. (1993) also found that greater parent-reported functional disability in chronic pain

accounted for nearly twenty percent of the variance in children's behavior problems. Lewis et al. (1993) reported that perceived illness demands were directly related to parental psychological functioning, which was indirectly related to child psychosocial functioning, defined by a measure of peer relationships. These findings should be qualified, however, by noting that in all of these studies parents completed ratings of both their own symptoms and those of their children, thus possibly confounding these relationships.

The healthy parent's adjustment to a partner's illness can be hypothesized to affect children's adjustment. For example, in a study of ill fathers, maternal uncertainty about a spouse's illness was associated with child-reported anxiety (Steele, Tripp, et al., 1997). There is also evidence that spouses perceive illness as more stressful than patients themselves do (Compas et al., 1994). However, the impact of parent-perceived stressfulness on children's adjustment has not been described. Nonetheless, these findings, in combination with findings related to children's perceptions of the parental illness, suggest that perceptions of illness are important to the adjustment of both parents and children.

As discussed previously, the sex of the ill parent may interact with the sex of the child in predicting child adjustment. However, main effects for parent sex have also been noted. Rotherham-Borus, Stein, and Lin (2001) reported that adolescents of parents with HIV described more emotional symptoms and sexual risk behaviors at two year follow-up when their mothers were ill than when their fathers were ill. However, more often ill fathers have been associated with more negative outcomes. Chun et al. (1993) found that children of ill fathers had less social competence on combined parent ratings than

children of ill mothers, although no sex differences were detected on parent- or teacher-reported behavior problems. Rodrigue and Houck (2001) also found that adolescents of fathers with a chronic health condition had significantly higher behavior problem scores on both maternal and self-report questionnaires than did adolescents of fathers without a chronic health condition. Adolescents of mothers with a chronic health condition did not differ from adolescents of mothers without a chronic health condition on any of the measures. However, it is important to note that none of the mean scores for these groups were in the clinical range.

One explanation for these sex-based findings is that many families rely on fathers as primary sources of financial support and decision making (Chun et al., 1993; Rodrigue & Houck, 2001). Role changes, as well as the impact of the illness on the mother, may lead to greater family instability when the father is ill (Compas et al., 1994). Indeed, there is some evidence to suggest that women respond to illness in their spouses more negatively than men do. Perceived severity of a spouse's cancer has been shown to be greater for wives whose husbands have cancer than for husbands whose wives are ill (Compas et al., 1994). In addition, Romano, Turner, and Clancy (1989) found that the relationship between spouse adjustment and patient disability was stronger when the patient was male.

Taken together, these findings indicate that the sex of the ill parent may be critical to understanding the impact parental illness has on children's adjustment. The experience of having an ill mother may particularly affect adolescent daughters because of potential redistribution of household responsibilities. Families with ill fathers may

experience greater changes in family roles, thus putting all members at greater risk for problems in adjustment.

### Illness factors

The impact of objective illness factors on the adjustment of children and adolescents has also been examined. Most commonly, researchers have examined the relationship between objective illness severity and child adjustment, yielding mixed results. Compas and colleagues (1994) found that the stage of a parent's cancer was unrelated to children's symptoms of internalizing problems and stress. They suggest that this result is consistent with cognitive models of stress in which appraisals are more important than actual disease characteristics. Other studies of objective illness characteristics have supported this conclusion. For instance, in a study of fathers with hemophilia, some of whom had contracted HIV, neither hemophilia severity nor HIV stage was significantly associated with child outcomes (Armistead, Klein, Forehand, & Wierson, 1997). Moreover, in a sample of inner city HIV-positive mothers, children's depression scores did not differ whether the women were symptomatic or asymptomatic (Biggar et al., 1998).

In contrast, other studies have linked parent reports of disease severity with more child adjustment difficulties. In a sample of low income, HIV-positive mothers, Forsyth and colleagues (1996) found that children whose mothers demonstrated symptoms of their disease reported significantly more symptoms of anxiety than did children whose mothers were asymptomatic. In another sample of adolescents with a parent who had AIDS, Rotherham-Borus and Stein (1999) found more self-reported internalizing symptoms as parent-reported ill health increased. However, this could also be interpreted

as resulting from adolescents' perceptions of their parents' health rather than direct effects of worsening illness.

Other characteristics of illness have been investigated less frequently. Length of diagnosis does not appear to be predictive of psychosocial functioning for children of parents with cancer (Compas et al., 1994; Lewis et al., 1993). Compas and colleagues (1994) noted that worse prognosis was associated with more adolescent stress-response symptoms, but was not related to symptoms of internalizing. Overall, the role of objective illness factors in children's psychological adjustment remains equivocal. However, it appears that objective illness factors may influence adults' and children's perceptions of the illness, which in turn may affect psychological adaptation.

#### Family factors

Several authors have emphasized the importance of family processes in children's adjustment to a family member's illness (e.g., Forehand et al., 1997; Kazak, 1989), thus implicating roles for dyadic relationships and family coping styles. At the same time, it has been suggested that family relationships may be placed at risk by physical illness (Armistead et al., 1995). While direct relationships between marital adjustment and child adjustment have not been found in this population (Chun et al., 1993; Lewis et al., 1993; Steele, Forehand, & Armistead, 1997), other family factors have been implicated in the functioning of children with chronically ill parents. Mothers with breast cancer who rated their families as more adaptable have been found to describe fewer behavioral and emotional difficulties in their children (Howes et al., 1994). Data have also indicated that ill parents from cohesive families report significantly less perceived physical and psychosocial impact of chronic illness than families characterized by conflict



(Stuijbergen, 1990). At the same time, adolescents of ill parents have been shown to perceive their families as having more conflict, lower cohesion, and poorer organization than adolescents of healthy mothers (Peters & Esses, 1985). Dura and Beck (1988) also found that members of families in which the mother had chronic pain or diabetes reported significantly less family cohesiveness than families of healthy parents. In addition, families of healthy parents also reported less conflict than families in which the mother had chronic pain, but no differences were noted in the amount of conflict in families with a mother who had diabetes. Finally, in a study of families in which a parent had rheumatoid arthritis, greater cohesion and expressiveness and less conflict were associated with decreased psychological symptoms (Hirsch, Moos, & Reischl, 1985). These factors were not related to functioning for children of healthy parents or those with a depressed parent. Given the importance of illness perceptions discussed earlier, it could be hypothesized that, for families coping with parental illness, cohesive families are at less risk for difficulties in adjustment than families in which conflict is prevalent because relationships in these families may be marked by more open communication styles.

Specifically, cohesive parent-child relationships may be one compensatory factor that lessens the risk for children and adolescents. As discussed earlier, research from the general stress literature has repeatedly supported the hypothesis that parent-child relationships are important to the adjustment of adolescents during stressful life events. Studies have substantiated this finding for adolescents and children facing the specific stressor of a chronically ill parent.

It appears that it is the quality, not the quantity, of adult relationships that is critical to adjustment. The mere presence of adults in the homes of mothers in the

advanced stages of HIV was not sufficient to predict better psychosocial functioning in children (Dorsey et al., 1999). This suggests that perceptions of relationship quality may be more relevant to children's functioning. For example, Kotchick, Summers, et al. (1997) found significant effects of perceived parental support for children who had an ill parent. Specifically, higher perceived parental social support predicted less parent-reported externalizing problems, less child-reported depression, and higher grade point averages. Extrafamilial support did not have a main effect on any of the child adjustment domains measured in the study. Also, children's reports of anxiety symptoms were not significantly related to social support. Interestingly, parental social support was also significantly related to parent reports of internalizing behaviors and child reports of depression when fathers reported that their illness had had a large impact on their lives, physically or psychologically. This is especially relevant to the families in the present study, since the pursuit of transplantation often coincides with illness that has had a significant psychological and physical impact on the parent.

Parent-child relationships have been identified as an important mechanism for promoting child adjustment in other studies of families coping with an ill parent (e.g., Lewis et al., 1993; Steele, Forehand, & Armistead, 1997). Greater conflict in parent-child relationships has been associated with more depressive symptoms, externalizing problems, and academic difficulties in children of fathers with HIV infection (Armistead et al., 1997). Kotchick, Forehand, et al. (1997) also found that more conflict in the mother-child relationship was associated with more child-reported internalizing and externalizing behaviors, as well as parent-reported social competence. Mothers with HIV reported significantly poorer relationship quality than did uninfected mothers, and both

mother- and child-reported psychosocial symptomatology was higher among children whose mothers were HIV-positive.

However, despite the important role parental support plays in the adjustment of children with a chronically ill parent, there are reasons to believe that they may be at risk for not having the support they need. In a retrospective study of grown children of parents who had had cancer, 20% of the women in the study reported negative feelings toward their ill parent and 15% described having problems with their ill parent's behavior during the illness (Leedham and Meyerowitz, 1999). Parent-child relationships may be affected when a parent is ill because the usual ways of interacting with parents can be altered by the effects of the illness, which may include emotional distress or impaired parenting (Lewis et al., 1993). For example, Kotchick, Forehand, et al. (1997) found that HIV-infected mothers reported less monitoring of their children than did uninfected women. Physical restrictions imposed by the illness may also threaten the quality of the ill parent-child relationship by limiting the amount and quality of interactions spent with the child (Kotchick, Summers, et al., 1997). Child perceptions of not wanting to bother an ill parent or of limited physical availability due to illness may also be detrimental to the parent-child relationship.

Sources of social support other than the ill parent would seem to take on increased importance to children when a parent is ill. However, the Kotchick, Summers, et al. (1997) study suggested only a limited role for extrafamilial social support. Therefore, a relationship with a healthy parent, when available, may prove to be critical for adolescents in families with such stressors. However, the healthy parent-child relationship may be compromised by demands of caring for an ill spouse and the effects

on that parent's psychological functioning and energy level (Kotchick, Summers, et al., 1997). Leedham and Meyerowitz (1999) found that 22% of their sample recalled having had negative feelings toward their healthy parent, similar to the percentage that recalled negative affect toward their ill parent. However, 33% of the women noted having had problems with their healthy parent's behavior (e.g. being too demanding) during the illness; this represents twice the number who recalled difficulties with their ill parent. This information suggests that while it seems probable that with regards to communication, relative to an ill parent, children may perceive a healthy parent as a more available source of support and may rely on this relationship to a greater degree, problems in this relationship are common and can represent threats to adolescent well being in this time of stress.

Unfortunately, much of the research in this area has focused on children of parents with HIV who often come from single-parent households (e.g., Forehand et al, 1998; Forsyth et al., 1996; Rotherham-Borus & Stein, 1999). Therefore, information on the effects of a healthy parent has been unavailable in many studies, thus limiting our knowledge. However, published research in other areas supports the idea that these relationships may be critical.

Studies have indicated that a single positive parental relationship may be sufficient to buffer adolescents from the negative effects of stress. In studying adolescents of divorced families, Forehand et al. (1987) found that adolescents with conflict-ridden relationships with both parents were rated by teachers as having lower cognitive competence, more externalizing behavior problems, and more internalizing behavior problems than adolescents with a good relationship with either one or both

parents. The notion that one positive parental relationship may be all that is necessary to foster good adolescent adjustment is an important consideration in families with an ill parent, given the factors that may interfere with the usual ways of interacting with an ill parent. A positive relationship with a healthy parent may be very beneficial to children's adjustment; however, this is not a foregone conclusion for many families. Forehand and colleagues (1997) found that children of fathers with hemophilia experienced poorer relationships with their mothers than with their fathers. Compas et al. (1994) found that wives perceived their spouses' illnesses as more severe than did husbands. Greater distress in wives of ill husbands may impair this healthy parent-child relationship and therefore place children of ill fathers at greater risk.

The relative importance of these relationships has been asserted in isolated studies. In a study of families of mothers with breast cancer, parents reported their children as having higher psychosocial functioning when the healthy parent (father) reported a better parent-child relationship, conceptualized as the frequency of interactions or "togetherness" experienced in the dyad (Lewis et al., 1993). The frequency of interactions between the ill parent and the child was not predictive of child functioning. The researchers suggest that a healthy parent may be an important route for information for the child about the parent's illness. This hypothesis is plausible and has been supported by findings in which parental feelings of uncertainty about a partner's illness were shown to be predictive of children's reports of anxiety beyond the predictive power of the children's own uncertainty (Steele, Tripp, et al., 1997).

Steele, Forehand, and Armistead (1997) further examined this relationship in a study of fathers with hemophilia, some of whom also were HIV-positive. High conflict



in both the mother (healthy parent)- and father-child relationships independently predicted child internalizing problems. However, the mother-child relationship accounted for nearly twice as much of the variance (19%) in child adjustment as did the father-child relationship (10%). These authors suggest that mothers in families subjected to severe stressors take on a role of “gatekeeper” whereby they protect the children from distress. Therefore, when this relationship is jeopardized by conflict, children may be at greater risk for psychological problems. However, considering this in combination with the Lewis et al. (1993) finding, it seems unlikely that it is the mother per se who serves as gatekeeper for families coping with parental illness. Rather, it is the individual in the role of the healthy parent, who may be perceived as more available or psychologically stable. However, our current understanding of the importance of the healthy parent is limited by the dearth of research on the topic and the use of measures examining the frequency of contact (Lewis et al., 1993) or the amount of conflict in the relationship (Steele, Forehand, & Armistead, 1997), which may not be the most relevant constructs for these families. Instead, it is proposed that parent-adolescent communication may be most meaningful.

Communication has often been considered an important, but understudied, element in the functioning of families coping with chronic illness. Studies of adolescents have indicated that better parent-adolescent communication is associated with better perceived family dynamics, such as family satisfaction and family cohesion (Barnes & Olson, 1985). These qualities may be buffers against the stress of having an ill parent. Indeed, Compas and colleagues (1996) called for more research on factors affecting children’s perceptions of cancer, specifically identifying the amount and type of



information received and abilities to process these facts as potentially relevant variables. Other researchers have suggested that children's uncertainty about parental illness and the negative consequences associated with this ambiguity are influenced by parents' own uncertainty about the illness, communicated directly or indirectly to the child (Steele, Tripp, et al., 1997).

Therefore, it may be that adolescent adjustment is affected by his or her cognitive understanding of the illness and its meaning to the family. This, in turn, implicates parent-adolescent communication as critical for providing information and support to the adolescent. These outcomes would also be expected to improve the parent-child relationship, earlier noted to be related to measures of adolescent adjustment. Indeed, better parent communication skills have been associated with less parent-child conflict (Armistead et al., 1997; Wierson & Forehand, 1992), which is often used to define parent-child relationships. Others have used this line of thinking to suggest that parental illness can interfere with usual interactions with the child, thus leading to behavior problems (Dorsey et al., 1999).

Indeed, in a qualitative, retrospective study of adult women who had had a parent with cancer, when asked what had hindered their coping with the stress of the illness, 22% identified a lack of honesty or disclosure (Leedham & Meyerowitz, 1999). When asked for advice they would give children with an ill parent, 69% of the women suggested that children keep lines of communication open. Further emphasizing the importance of communication in this population, 87% of participants in the open-ended interview format advised parents to be honest with their children, and 71% recommended talking to their children in this situation. In summary, the responses of the grown

children in this study suggest that they perceived open family communication as a critical factor in their adjustment to parental illness.

It has been recommended that chronically ill parents provide their children with as much information as developmentally appropriate because “information and open communication may work to reduce the child’s uncertainty” (Steele, Tripp, et al., 1997, p. 587). Other authors have recommended that increasing parental emotional availability and assisting the child’s self-expression are important clinical recommendations for helping children adjust to having a physically ill parent (Armsden & Lewis, 1993). Open parent-adolescent communication may facilitate the implementation of these recommendations. In addition, good communication would appear to signify a positive parent-child relationship characterized by openness and a lack of major conflicts. Finally, having satisfying parent-adolescent relationships may simply represent one less stressor that adolescents in these families must contend with in maintaining their own mental health, thus contributing to better adjustment. However, little research regarding the impact of parent-adolescent communication exists for this population despite calls for research on “the underlying processes leading to health and disorder” (Hirsch, Moos, & Reischl, 1985, pp. 163).

## CHAPTER 3 AIMS AND STUDY JUSTIFICATION

### Purpose of the Study

The primary purposes of the study were to better describe adolescent perceptions of their relationships with healthy and ill parents and to better delineate the relative influence of these parent-adolescent relationships on the adjustment of adolescents in families with an ill parent. Previous studies have suggested that adolescents may be at elevated risk for adjustment difficulties, but they have not been the focus of considerable study. The present study examined the following specific hypotheses.

### Hypotheses

#### Hypotheses Related to Levels of Adolescent Adjustment

1. It was hypothesized that because parental illness can draw attentional, emotional, and material resources away from an adolescent, mean scores on measures of psychological symptoms of depression and anxiety would be elevated relative to normative data.
2. It was hypothesized that, in agreement with previous studies (e.g., Compas et al., 1994; Rodrigue & Houck, 2001), adolescents with ill same sex parents would have more adjustment difficulties than those whose opposite sex parents were ill.

#### Hypotheses Related to Parent-Adolescent Communication

3. It was hypothesized that because illness may represent a threat to security in the parent-adolescent relationship through perceived unavailability or fear of parental

death and because of adolescent concerns for the effects of stress on an ill parent, adolescents would perceive poorer communication quality with their ill parents compared to their healthy parents.

4. It was hypothesized that because healthy parents may have more contact with adolescents, be perceived by their children as more emotionally available than ill parents, and therefore be relied upon to a greater degree for emotional support, communication with the healthy parent would be a stronger predictor of adolescent adjustment than communication with the ill parent. It was hypothesized that this pattern would remain after testing for effects of adolescent age, sex, perceived illness severity, and socially desirable responding.
5. It was hypothesized that, consistent with the finding of Forehand et al. (1987), adolescents with at least one positive parental relationship would have fewer reported symptoms of depression and anxiety than those with average or negative parent relationships.

#### Hypotheses Related to Ill vs. Healthy Parent Reports of Adolescent Adjustment

6. Because it was hypothesized that adolescents communicate better with healthy parents than with ill parents, thus allowing healthy parents greater awareness of adolescent functioning, it was also hypothesized that healthy parent reports of adolescent symptoms would better reflect adolescents' self-descriptions of adjustment than ill parent reports. It was expected that healthy parents would endorse more problem behaviors and that healthy parent reports of symptomatology would be more strongly associated with adolescent reports of their own symptoms.

## CHAPTER 4

### METHOD

#### Participants

Thirty-eight two-parent families with adolescents participated in the study. To be included in the study, families were comprised of at least one parent with a chronic, life-threatening illness, one parent who did not have such a condition, and an adolescent between the ages of 12 and 17. In families with more than one adolescent, only one was randomly chosen to be invited to participate. Because the major hypotheses of the study were related to communication between parent and child through a consistent relationship, only families in which all three members had shared the same residence for the previous six months were included. All adolescents were aware of their parent's illness and treatment.

#### Ill Parents

Chronically ill parents were identified through transplant, radiation oncology, and dialysis clinics and had a variety of diagnoses, including liver disease (32%), cancer (29%), kidney disease (24%), heart disease (11%), and lung disease (5%). Fathers comprised 66% of the sample. This statistic is partly a result of the fact that more males than females are evaluated for transplantation at the university medical center where the study was conducted. Men comprise 60% of liver candidates, 85% of heart candidates, 60% of kidney candidates, 49% of lung candidates, and 50% of bone marrow candidates.

While variation in nature and severity of diseases in the present sample occurred, all patients had active, significant illnesses requiring ongoing medical treatment.

Because the objective of the study was not to examine the stress of a treatment (e.g., chemotherapy, transplant) itself, but rather the experience of having an ill parent, all patients with the aforementioned illnesses seen in participating clinics at the hospital were eligible for inclusion in the study.

The age of the ill parents in the study ranged from 32 to 63 years, with a mean age of 44.74 years and a standard deviation of 6.23 years. Educationally, 13% of the patient sample had completed less than the twelfth grade, while 45% had graduated high school. Thirty-four percent had attended at least one year of college, and an additional 8% had pursued post-graduate education. The patient was a biological parent to the participating adolescent in 82% of the families. The parent with a chronic illness was a biological father in 18 families, a biological mother in 13 families, a step-father in 6 families, and a live-in boyfriend in one family. One ill father experienced a health crisis shortly after the family began participation in the study and was unable to complete the CBCL regarding his daughter.

Parents had been hospitalized between 0 and 15 times prior to participation in the study. The average number of hospitalizations was 3.84 with a standard deviation of 3.28. Time since diagnosis ranged from 3 months to 32 years, 7 months. Thirty-four percent of the sample had been diagnosed within the past year. An additional 26% had been diagnosed between one and three years prior to participation in the study, 13% had been diagnosed for between three and five years, and 26% had been diagnosed for more than five years.



### Healthy Parents

The age of the healthy parents in the present sample ranged from 28 to 59 years. The average age was 43.67 years, with a standard deviation of 7.40 years. Five percent of the healthy partners had not completed high school, while 49% had graduated the twelfth grade. Forty-one percent had completed some college, and 5% had attended graduate school. Healthy partners were biological parents to 84% of the adolescents in the study. Of the 38 participating families, 24 healthy parents were biological mothers, 8 were biological fathers, 2 were step-mothers, and 4 were step-fathers. Three healthy parents were unable to be contacted for study participation.

### Adolescents

Females represented 66% of the adolescents participating in the study. The average age was 14.92 years with a standard deviation of 1.65 years. Of the adolescents participating in the study, 3% were in the sixth grade, 13% in the seventh grade, 32% in the eighth grade, 16% in the ninth grade, 21% in the tenth grade, 5% in the eleventh grade, and 11% in the twelfth grade. The sample was primarily Caucasian (84%); thirteen percent of the sample was Black, and 3% was of Hispanic descent.

### Family demographics

Family composition included only the two parents and adolescent in 32% of the families studied, while 50% had four individuals living in the home. Eighteen percent of the families had five or more members residing together. Family income was less than \$10,000 for 5% of participating families, between \$10,000 and \$19,999 for 8%, between \$20,000 and \$29,999 for 19%, between \$30,000 and \$39,999 for 16%, between \$40,000 and \$49,999 for 14%, and greater than \$50,000 for 38% of the families.

For 63% of the families, parents reported that their adolescent was immediately told of the parent's illness at the time of diagnosis. On average, adolescents in the current study had been aware of their parent's illness for 34 months prior to the study interview. However, there was a great deal of variability in the amount of time adolescents had been coping with this stressor, with a range of 2 to 165 months. Forty percent of the sample had been aware for 12 months or less, 29% had been aware for 13 to 36 months, 13% had had knowledge of it for 37 to 60 months, and 18% had been coping with this stressor for more than five years.

Of the 38 families who took part in the study, 18 included an ill father with an adolescent daughter, 7 had an ill mother with an adolescent daughter, 7 had an ill father with an adolescent son, and 6 had an ill mother with an adolescent son.

#### Procedure

All study procedures were approved by the university's institutional review board. Families were recruited for the study during routine patient clinic appointments. Patients (and spouses, when available) were approached at the time of their appointment when informed consent procedures, including permission to contact their adolescent child, were conducted. Ill parents completed a family demographic questionnaire and the Child Behavior Checklist (CBCL; Achenbach, 1991a). When present, healthy parents also completed a CBCL at this appointment. When parents were not available to complete questionnaires in person, these instruments were conducted via phone interviews.

In all but three cases, adolescents were not present during their parent's appointment and were subsequently contacted by phone. The study was explained to all adolescents and verbal assent was obtained. Adolescents completed the Reynolds

Adolescent Depression Scale (RADs; Reynolds, 1987), Revised Children's Manifest Anxiety Scale (RCMAS; Reynolds & Richmond, 1985), Impact of Event Scale (IES; Horowitz, Wilner, & Alvarez, 1979), Parent-Adolescent Communication Scale (PACS; Olson, 1985), and a single item regarding the perceived severity of their parent's illness (Compas et al., 1994). While the majority of responses were obtained by telephone, copies of these measures were sent home with participating parents for the adolescents to reference during the telephone administration of the questionnaires. Adolescents who completed the interview received a \$10 gift certificate.

### Measures

The outcome measures described below were selected for the present study for several reasons. First, they were designed to assess both general psychological adjustment in adolescents (RADs and RCMAS) as well as stressor-specific distress (IES). Second, adequate reliability and validity have been demonstrated for all of the measures and are described below. Finally, the potential range of scores for each of the instruments is large, and, with the exception of the RADs, each of the outcome measures had been used in previous studies examining adjustment to parental illness and had demonstrated significant effects.

### Demographics (Appendix)

A demographic questionnaire was completed by the patient and obtained background information regarding the patient, his or her partner, and the adolescent. Medical history information, such as diagnosis, illness duration, and how long the adolescent was aware of the illness, was also obtained via this questionnaire. To assess other concurrent stressors, parents also reported whether their adolescent had experienced

any of nine events in the past year. These included the death of a friend, death of a relative, academic problems, change in residence, family financial problems, school change, legal problems, parental divorce, or parental remarriage.

### Perceptions of Illness Questionnaire

Consistent with Compas and colleagues (1994), adolescent perceptions of illness severity were assessed using the question, “How bad do you think your parent’s illness is?” Adolescents responded on a 5-point Likert scale ranging from 1 = not at all bad to 5 = extremely bad.

### Reynolds Adolescent Depression Scale (RADs)

The RADs (Reynolds, 1987) is a 30-item self-report measure of depressive symptoms for adolescents. Adolescent total scores were compared using the standardization sample percentile rankings based on sex and grade (Reynolds, 1987). These were converted to T scores for analyses.

The measure has demonstrated good reliability and validity. For the standardization sample, the internal consistency reliability coefficient was .92. Test-retest reliability at six weeks was .80, at three months was .79, and at one year was .63. The standard error of measurement is approximately four raw score points (Reynolds, 1987). Convergent validity has been demonstrated with other self-report depression instruments, such as the Beck Depression Inventory, Center for Epidemiological Studies-Depression scale, and the Children’s Depression Inventory. Each of these measures yielded correlation coefficients with the RADs of .68 or higher (Reynolds, 1987). Similarly, concurrent validity with a depression interview, the Hamilton Rating Scale, has been established with a correlation coefficient of .83 (Reynolds, 1987).

The RADS contains an item regarding self-injurious behavior, “I feel like hurting myself,” which was not asked during adolescent interviews. A conservative approach was taken with this deletion and the lowest possible score (“almost never”) was used to calculate total depression scores.

#### Children’s Manifest Anxiety Scale- Revised (RCMAS)

The RCMAS (Reynolds & Richmond, 1985) is a 37-item self-report questionnaire for children 6 to 19 years of age. It assesses the presence or absence of anxiety-related symptoms, yielding a total anxiety scale score, three subscales scores (Physiological, Worry and Oversensitivity, and Concentration), and a Lie scale. The Lie scale contains seven items and provides an index of socially desirable responding. As with the RADS, all scale scores were standardized using age and sex norms, and T scores were used in all analyses, except where noted.

Adequate internal consistency reliability for the total anxiety scale score is established, with alpha greater than .80 (Reynolds & Paget, 1983). In addition, it is highly correlated ( $r = .85$ ) with the trait scale of the State-Trait Anxiety Inventory for Children, suggesting good convergent validity (Reynolds, 1980).

#### Impact of Event Scale (IES)

The IES (Horowitz, Wilner, & Alvarez, 1979) is a 15-item questionnaire assessing the subjective distress of a particular event. In addition to yielding a Total Stress score, the scale is commonly divided into two subscales, Intrusion and Avoidance, as reported by the authors. The validity of this factor structure in adults has been supported by Zilberg, Weiss, and Horowitz (1982), however the presence of a third factor, Emotional Numbing (Schwarzwald, Solomon, Weisenberg, & Mikulincer, 1987)



or Sleep Disturbance (Larsson, 2000), has been suggested in other replication studies with adults. Despite this, the original two factor structure remains commonly used in the trauma literature.

Horowitz, Wilner, and Alvarez (1979), using a sample of adults experiencing bereavement or personal injury, reported test-retest reliability of .87 for the Total stress score, .89 for the Intrusion subscale, and .79 for the Avoidance subscale. Specific to the present study, Compas and colleagues (1994) used the IES in a study of children of parents with cancer and found internal consistency reliability to be adequate for adolescents ( $\alpha = .67$ ). Adequate validity data has been presented as well. Horowitz, Wilner, and Alvarez (1979) found lower scores on the measure after patients had undergone psychotherapy, suggesting that the measure is sensitive to decreases in the stressfulness of an event resulting from time and therapy.

The IES, while originally used with adults, has been incorporated into studies of children and adolescents. Psychometric properties appear similar to those found among adults, although the third factor, Emotional Numbing, has been identified in two studies analyzing the measure's properties with adolescents and young adults (Sack, Seeley, Him, & Clarke, 1998; Yule, Bruggencate, & Joseph, 1994). Because of the ambiguous findings regarding this third factor, the present study used the Total Stress score as the main dependent variable for analyses involving the IES.

Because of the event-specific nature of the IES, normative data do not exist. However, several studies have used the instrument with children and adolescents, thus providing information for comparison to other samples (see Table 2). The majority of these studies have administered the IES to victims of large-scale accidents (e.g., cruise



ship sinking, dormitory fire) or violence (e.g., war, parental homicide). In addition, one study investigated lifetime prevalence of significant negative life events (e.g., family member with a substance abuse problem, parental separation or divorce) and reported mean IES scores for their sample of adolescents who had experienced each event (Joseph, Mynard, & Mayall, 2000). This provides additional data by which to compare post-traumatic stress symptoms among adolescents experiencing significant stressors.

Table 2

Comparison Scores on the Impact of Event Scale for Children and Adolescents

Event	Author/ Year	Age	Time since event	Sex	<u>N</u>	Mean
Taken hostage at school by armed mental patient	Vila et al. (1999)	7.5-9.5 yrs.	6-8 wks.	Both	21	33.6
			16-18 wks.		20	24.5
			28-30 wks.		16	17.3
			82-84 wks.		18	20.1
Indirectly exposed to hostage incident		7.5-9.5 yrs.	16-18 wks.	Both	21	25.5
					21	14.8
					18	18.0
Cruise ship sinking	Yule & Udwin (1991)	14-16 yrs.	10 days	Female	24	35.5
			5 mos.		24	35.33
Bus accident	Stallard & Law (1993)	14 yrs.,	6 mos.	Both	7	31.0
		9 mos.-16 yrs., 3 mos.				
Dormitory fire	Jones & Ribbe (1991)	14-19 yrs.	4 mos.	Male	25	28.0
Ferry sinking	Yule & Williams (1990)	12-14 yrs.	3-6 mos.	Both	7	46.9
			12-15 mos.	Male	6	34.1
				Female	4	43.8
Witnessed parent murder/ attempted familicide	Malmquist (1986)	5-10 yrs.	Unreported	Both	16	56.9
Coach accident	Curle & Williams (1996)	6-18 yrs.	2 yrs.	Both	25	16.08
				Male	11	10.6
				Female	14	20.4

Table 2. Continued

Event	Author/ Year	Age	Time since event	Sex	n	Mean
Life threat to family member or friend (accident, injury, or illness) <sup>a</sup>	Joseph et al. (2000)	11-16 yrs.	Unreported	Male	90	22.15
				Female	122	27.74
Life threat to self (accident, injury, or illness) <sup>a</sup>				Male	46	16.95
				Female	42	25.06
Witnessed attack or physical assault				Male	55	12.76
				Female	48	19.48
Personal assault <sup>a</sup>				Male	36	16.63
				Female	25	34.40
Fire or natural disaster <sup>a</sup>				Male	25	12.87
				Female	12	25.82
Parental separation or divorce				Male	49	23.29
				Female	69	29.64
Family member with substance abuse				Male	21	23.41
				Female	31	31.64
Trouble with the law				Male	44	15.16
				Female	26	17.65

Note. <sup>a</sup>Mean female score significantly higher than males in Joseph, Mynard, and Mayall (2000) sample

#### Parent-Adolescent Communication Scale (PACS)

The PACS (Olson, 1985) measures perceptions of both positive and negative communication between adolescent and parent. The PACS focuses on the exchange of ideas between adolescent and parent, trust between them, and the emotional tone of interactions (Jacob & Tennenbaum, 1988). The adolescent form used in this study contains 20 items that adolescents separately rated in relation to his or her mother and father. The measure was administered in its entirety in relation to one parent and then

completed for the other parent; the order in which it was administered (mother vs. father) was counterbalanced.

Each item was rated on a 5-point Likert scale from “strongly disagree” to “strongly agree.” Items on the PACS are phrased in both negative and positive terms. The PACS generates a total score as well as two subscale scores. The Open Family Communication subscale reflects feelings of free expression and understanding in parent-adolescent interactions. Sample items include “When I ask questions, I get honest answers from my mother/father” and “I find it easy to discuss problems with my mother/father.” The second subscale, Problems in Family Communication, measures negative interaction patterns and hesitancy to disclose concerns. Examples of items on this subscale include “My mother/father has a tendency to say things to me that would be better left unsaid” and “I don’t think I can tell my mother/father how I really feel about some things.” Good internal consistency of the entire measure has been established ( $\alpha = .88$ ; Olson, 1985). Cronbach’s alphas for Open Family Communication and Problems in Family Communication were .87 and .78, respectively. Total score test-retest reliability over 4 to 5 weeks was .60.

Olson (1985) has reported a factor analysis supporting the construct validity of the measure scales (Jackson, Bijstra, Oostra, & Bosma, 1998). Concurrent validity of the PACS has been supported by consistently significant and elevated correlations (.43 - .73) between adolescent reports on the Cohesion subscale of the Family Adaptability and Cohesion Evaluation Scale (FACES-III) and both the PACS total (Brown & Mann, 1990) and subscale scores (Morrison & Zetlin, 1988; Tulloch, Blizzard, & Pinkus, 1997).

Jackson et al. (1998) also found that the PACS correlated significantly with the Family Satisfaction Scale.

This same study found that the PACS was significantly correlated with adolescent reports of the outcomes of arguments with both their mothers and fathers. Poorer communication (less open and more problems) was associated with greater frustration, greater escalation, and less intimacy. Poorer communication was also associated with an aggressive approach to disagreement and negatively correlated with an approach to disagreement characterized by seeking compromise, suggesting that conflict is associated with scores on the PACS. In a separate study by Baer (1999), higher scores on the Open Communication scale of the PACS significantly predicted decreased family conflict in three different ethnic groups of adolescents.

#### Child Behavior Checklist (CBCL)

The CBCL (Achenbach, 1991a) measures 4- to 16-year-old children's competencies and behavior problems as reported by their parents. For this study, only the behavior problem scales were collected. Parents rated 112 behaviors as "not true," "somewhat or sometimes true," or "very true or often true" in the past six months. Responses on the CBCL yield scores on three broad scales: internalizing behaviors, externalizing behaviors, and total behavior problems. Eight subscales have also been established. Only the 14-item Anxious/Depressed subscale was used for the present study.

Adequate reliability and validity data have been reported (Achenbach, 1991a). Seven-day test-retest reliability correlations for the Internalizing, Externalizing, and Total Problems scales were .89, .93, and .93, respectively. Achenbach (1991a) also reported a

correlation of .76 for interrater reliability between parents for the Total Problems scale. Parent correspondence of .66 and .80 were reported for the Internalizing and Externalizing scales, respectively. Construct validity has been assessed by comparing scores on the CBCL to scores on the Conners Parent Questionnaire, yielding a correlation of .81 for total problems, .72 for internalizing symptoms, and .88 for externalizing behaviors. The correlation between the Total Problems scores on each scale was .82.

Standardized T scores are based on normative data for age and gender; these standardized scores were used in all analyses. Clinical cutoffs have been established for the Total Problems, Internalizing, and Externalizing scales whereby a T score of 60 or greater is considered deviant. The clinical cutoffs for these scales have been shown to significantly discriminate between children referred for psychological services and those not referred. For the Anxious/Withdrawn subscale, a T score of 67 is recommended as the clinical cutoff.

## CHAPTER 5 RESULTS

### Preliminary analyses

To assess the reliability of adolescent-completed measures in the present sample, alpha coefficients were calculated. Coefficients ranged from .72 to .90 for the total sample suggesting adequate internal consistency reliability for all instruments used. In addition, alpha coefficients were calculated for males and females separately; these values ranged from .60 to .91 (see Table 3). Alpha coefficients were not calculated for the CBCL as it is an established measure and its reliability was assumed.

Table 3

Alpha coefficients of adolescent-completed measures for total sample, males, and females

Measure	Total		Males		Females	
	<u>n</u>	$\alpha$	<u>n</u>	$\alpha$	<u>n</u>	$\alpha$
RADS, Total score	37	.89	13	.83	24	.91
RCMAS, Total score	38	.90	13	.87	25	.91
IES, Total score	38	.82	13	.68	25	.86
PACS, Total score- mother	38	.85	13	.81	25	.86
PACS, PFC score- mother	38	.78	13	.61	25	.80
PACS, OFC score- mother	38	.87	13	.87	25	.87
PACS, Total score- father	38	.88	13	.90	25	.88
PACS, PFC score- father	38	.80	13	.79	25	.81
PACS, OFC score- father	38	.87	13	.87	25	.88

Note. RADS = Reynolds Adolescent Depression Scale; RCMAS = Revised Children's Manifest Anxiety Scale; IES = Impact of Event Scale; PACS = Parent- Adolescent Communication Scale, PFC = Problems in Family Communication, OFC = Open Family Communication

Data were examined for outliers by examining ranges. To determine the retention and deletion of possible outliers, Hair et al. (1998) recommend that data should be



eliminated only if there is proof that they are completely aberrant and do not represent any occurrence in the population. Using this guideline, no values in this data set were believed to be nonrepresentative of the population being considered.

To assess normality,  $z$  values for skewness and kurtosis were calculated (see Table 4). A critical value of  $\pm 1.96$ , corresponding to a .05 error level, was chosen. Values for all measures were below this critical value, with the following exceptions, which suggested abnormal distributions. Both ill and healthy parent reports on the CBCL Anxious/ Depressed subscale were significantly positively skewed. In addition, ill parent reports on this subscale were more sharply peaked than a normal curve. This distribution is likely a function of both the Achenbach (1991a) scoring system, which does not allow for subscale scores below 50, and the fact that few parents reported significant levels of symptoms on this subscale. Due to its poor statistical properties with this sample, further analyses were not conducted using this subscale as normed by Achenbach.

The ratings of perceived illness severity were significantly negatively skewed. The range of values available on the Likert scale was five, and 90% of the adolescents in the sample rated their parent's illness as "3" or higher on the scale. Because the variable was not a continuous one, no transformation was conducted.

Despite assurances given during adolescent interviews, the possibility was considered that adolescents might consider their responses relevant to their parents' candidacy for transplant, and thus attempt to present in a favorable light. As noted earlier, the RCMAS Lie scale is an index of socially desirable responding. Four of the respondents were above the 90<sup>th</sup> percentile on this measure. Correlations were computed between the RCMAS Lie scale raw scores and adolescent self-report independent (ill and

healthy parent PACS T scores) and dependent (RCMAS and RADS T scores, IES raw scores) variables to determine whether adolescent responding appeared to have been influenced by social desirability. Using a one-tailed test, findings indicated a significant positive correlation between ill parent ( $r = .29$ ), but not healthy parent ( $r = .13$ ), communication and socially desirable responding on the RCMAS. No significant relationships emerged on correlations between dependent measures and the RCMAS Lie scale. Despite its correlation with ill parent communication, because the social desirability measure was not also associated with any of the dependent variables, it was not included in the final regression models.

Table 4

Shape descriptors of variable distributions

Measure	Skewness		Kurtosis	
	Statistic	z value	Statistic	z value
RCMAS, Total score	.343	.864	-.911	-1.146
RCMAS, Lie score	-.339	.854	-.181	-.228
RADS, Total score	.151	.380	-.397	-.499
IES, Total score	.745	1.877	.346	.435
CBCL, Ill parent- Total Problems	.120	.302	-.380	-.478
CBCL, Ill parent, Internalizing	.100	.252	-.224	-.282
CBCL, Ill parent, Externalizing	.425	1.071	-.285	-.358
CBCL, Ill parent, Anxious/ Depressed	1.915	4.824	3.389	4.263
CBCL, Healthy parent, Total Problems	-.421	-1.060	.012	.015
CBCL, Healthy parent, Internalizing	-.310	-.781	-.537	-.675
CBCL, Healthy parent, Externalizing	.144	.363	-.621	-.781
CBCL, Healthy parent, Anxious/ Depressed	1.071	2.700	-.198	-.249
Perceived illness severity	-.751	-1.892	.378	.475
PACS, Ill parent, Total score	.094	.237	-.903	-1.136
PACS, Healthy parent, Total score	-.525	-1.322	-.187	.235
Adolescent age	.223	.562	-1.101	-1.385

Note. Z values derived by dividing the statistics by the appropriate standard errors of .397 (skewness) and .795 (kurtosis).

### Primary analyses

#### Hypothesis 1: Adolescent Adjustment to Parental Physical Illness

It was hypothesized that mean scores on measures of depression and anxiety would be elevated relative to normative samples. This hypothesis was partially supported. Means and standard deviations for adolescents' self-reports of depression (RADS) and anxiety (RCMAS and IES) are presented in Table 5. Means and standard deviations for parent reports of internalizing, externalizing, total problems, and symptoms of depression/anxiety on the CBCL are presented in Table 6.

Table 5

#### Means and standard deviations of self-report measures of adolescent adjustment

Measure	<u>n</u>	<u>M</u>	<u>SD</u>
RADS, Total score <sup>a</sup>	38	48.10	8.72
RCMAS, Total score <sup>a</sup>	38	49.21	10.84
RCMAS, Lie Scale <sup>b</sup>	38	10.68	2.43
IES, Total score	38	27.87	14.30

Note. RADS = Reynolds Adolescent Depression Scale; RCMAS = Revised Children's Manifest Anxiety Scale; IES = Impact of Event Scale.

<sup>a</sup>T score conversion. <sup>b</sup>Scaled score conversion.

Table 6

#### Means and standard deviations of parent-report measures of adolescent adjustment

Measure	Healthy (n = 35)		Ill (n = 37)	
	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>
CBCL, Total Problems	49.11	10.73	49.46	8.70
CBCL, Internalizing Problems	48.63	9.96	48.38	10.08
CBCL, Externalizing Problems	49.57	9.74	49.65	8.03

Note. Values represent T score conversions. CBCL = Child Behavior Checklist.

Results related to symptoms of adolescent depression did not support the hypothesis. The mean score on the RADS was in the average range and represented a subclinical level of responding. A Welch's  $\chi^2$  test was conducted to compare the raw

score measure mean of the present sample with that of the normative sample. There was no significant difference between the current sample and the standardization sample,  $t(10) = 1.41, p > .05$ . On the RADS a raw score of 77 or above has been established as a clinical cutoff identifying a level of symptomatology representative of clinical depression (Reynolds, 1987). Five percent of adolescents in the present study responded at this level of clinical significance. This is lower than anticipated, as expected percentages in the clinical range of scores have been reported as 8% for boys and 14% for girls (Reynolds, 1987).

Adolescent responses on the RCMAS also did not support the hypothesis. The average score was in the subclinical range for the Total score. Welch's  $t$  test indicated that there was no significant difference between the current sample of adolescents and the normative group for the RCMAS Total score,  $t(10) = .055, p > .05$ . Consistent with the recommendation of Reynolds and Richmond (1997), scores greater than one standard deviation of the mean were interpreted as outside the normal range on the RCMAS. Eighteen percent of the present sample was beyond this cutoff. While the measure manual does not indicate expected percentages in the clinical range, using the cutoff of one standard deviation suggests that 16% of the sample would be expected to score at this level.

Results for the IES partially supported the hypothesis. Adolescent responses on the IES yielded a mean total score below the clinical cutoff of 35 recommended by Neal, Busuttill, Rollins, Herepath, Strike, and Turnbull (1994). As discussed earlier, due to the context-specific nature of the measure, normative data for the IES for the population being considered does not exist. In addition, the study by Compas et al. (1994) did not

use the complete IES with children and adolescents, therefore no comparison sample is available for the IES. However, using the standard of Neal et al. (1994), 31.6% of the adolescents in the present sample reported significant levels of stress-related symptoms.

Parent-reports of psychological symptoms did not support the hypotheses. As noted earlier, Achenbach (1991a) has identified a T-score of 60 or above as clinically significant on the CBCL Total Problems, Internalizing, and Externalizing scales. For subscales of the CBCL, such as the Anxious/Depressed subscale, a T-score of 67 or above is the recommended clinical cutoff (Achenbach, 1991a). The means on all scales (Total Problems, Internalizing, Externalizing, and Anxious/Depressed) were within normal limits for both healthy and ill parents. Fourteen percent of healthy parents ( $n = 35$ ) and 11% of ill parents ( $n=37$ ) described their adolescents in the clinical range of scores on the Total Problems scale. On the Internalizing scales, 9% of healthy parents and 14% of ill parents reported clinically elevated levels of symptoms, while 17% and 14% of healthy and ill parents, respectively, indicated clinically significant elevations on the Externalizing scale. None of the healthy parents and 5% of the ill parents reported clinically meaningful elevations on the Anxious/ Depressed subscale of the CBCL. The clinical range of the CBCL represents the highest 2% of scores from the normative sample.

Secondary analyses were conducted to assess the influence of demographic influences on the adjustment scores observed and to determine variables associated with dependent measures for inclusion as covariates in subsequent regression analyses. For this reason, a family wise error rate was not used and a more liberal error rate (.05) was determined as a cutoff.



Adolescent sex differences on measures of adjustment were examined using independent samples t-tests. No significant sex differences emerged on adolescent self-report measures (RADs, RCMAS, or IES). On the parent-report CBCL, ill parents rated males as having significantly higher levels of total problems,  $t(35) = 2.45$ ,  $p < .05$ , and internalizing problems,  $t(35) = 2.71$ ,  $p < .05$ , than females. No other significant sex differences were reported on parent-report measures of adolescent behavior (see Table 7).

Differences based on the sex of the ill parent were examined using independent samples t-tests. Adolescents whose mothers were ill did not differ significantly from adolescents whose fathers were ill on adolescent-report or parent-report measures of adjustment.

Table 7

Means on measures of adolescent adjustment by sex

Measure	Males (n = 13)		Females (n = 25)	
	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>
RCMAS, Total score	49.77	10.58	48.92	11.17
RADS, Total score	50.14	7.27	47.04	9.35
IES, Total score	29.62	11.58	26.96	15.67
CBCL, Ill parent- Total Problems*	53.92	8.27	47.04	8.09
CBCL, Ill parent, Internalizing*	54.00	10.16	45.33	8.81
CBCL, Ill parent, Externalizing	52.31	7.19	48.21	8.22
CBCL, Healthy parent, Total Problems	50.08	8.40	48.61	11.91
CBCL, Healthy parent, Internalizing	47.17	7.32	49.39	11.18
CBCL, Healthy parent, Externalizing	48.75	6.74	50.00	11.10

Note. Values represent T score conversions for all measures, except IES. RCMAS = Revised Children's Manifest Anxiety Scale; RADS = Reynolds Adolescent Depression Scale; IES = Impact of Event Scale; CBCL = Child Behavior Checklist.

\* Significant difference between males and females,  $p < .05$

Correlation coefficients were calculated between adolescent age and dependent (RCMAS, RADS, IES, and CBCL Total and Internalizing Problems for both ill and healthy parents) variables. One correlation emerged as significant in one-tailed tests; IES



scores were positively correlated with age ( $r = .36, p < .05$ ). All other correlation coefficients were not significant at a .05 probability level (see Table 8).

Table 8

Correlations between demographic variables and study measures

Measure	Adolescent age	Time since diagnosis
PACS- Ill	-.11	.08
PACS- Healthy	-.22	-.20
RCMAS	.21	.04
RADS	.20	.14
IES- Total	.36*	.10
CBCL Total- Ill	.18	.26
CBCL Total- Healthy	.09	.23
CBCL Internalizing- Ill	.13	.19
CBCL Internalizing- Healthy	.01	.05
Perceived Illness Severity	.19	.13

Note. \*  $p < .05$ . All significance tests are one-tailed. PACS = Parent-Adolescent Communication Scale; RCMAS = Revised Children's Manifest Anxiety Scale; RADS = Reynolds Adolescent Depression Scale; IES = Impact of Event Scale; CBCL = Child Behavior Checklist

Correlation coefficients were calculated between the amount of time the adolescent had been aware of his or her parent's illness and outcome measures. These were conducted with two-tailed significance tests as there were no hypotheses regarding whether higher scores would be associated with the acute knowledge phase (i.e., less time) or with greater time spent coping with the stressor. No correlation coefficients approached significance on any parent report measures of behavior problems (CBCL Total Problems or Internalizing) or self-report measures of adjustment (RADS, RCMAS, or IES) (see Table 8).

To further ensure that no differences existed between those who had learned of their parent's illness relatively recently and those who had been aware of it for a longer period of time, independent samples t-tests were conducted between adolescents who had

been aware of the disease for one year or less and those who had been aware for more than one year. No significant differences emerged.

The impact of adolescents' beliefs regarding the severity of their parents' illness was examined. On the five-point Likert scale of perceived illness severity, 5% of adolescents rated their parent's illness as 1, "not at all bad", 5% rated it 2, 26% rated it 3, 37% rated it 4, and 26% rated it 5, "extremely bad." The mean rating for the total sample was 3.72, with a standard deviation of 1.08. Ratings differed by sex as well, with girls ( $M = 3.94$ ,  $SD = .74$ ) describing their parent's illness as more severe than boys ( $M = 3.31$ ,  $SD = 1.49$ ). However, this difference was not statistically significant,  $t(15) = -1.44$ ,  $p > .05$ . In addition, adolescent ratings of perceived illness severity were not significantly correlated with any self-report measures (i.e., RADS, RCMAS, IES, PACS).

Using previous research that has suggested that adolescents who experience three or more stressors appear to be more vulnerable to psychological distress, adolescents whose parents reported two or more stressors (in addition to parental illness) on the demographic questionnaire were compared to those whose parents did not. Using independent samples t-tests, no significant differences emerged for the RCMAS, RADS, IES, or either ill or healthy parent CBCL total problem reports. No differences emerged for healthy parent reports of internalizing behaviors; however, adolescents with two or more additional stressors were rated by parents as having significantly more internalizing symptoms than those who did not.

#### Hypothesis 2: Effects of Same Sex Ill Parents

It was hypothesized that adolescents with ill same sex parents would have more psychological symptoms than those whose opposite sex parents were ill. This hypothesis

was not supported. Two (sex of adolescent)  $\times$  2 (sex of ill parent) analyses of variance (ANOVAs) were conducted to assess differences on adolescent adjustment measures as a function of the interaction between the sex of the adolescent and the sex of the ill parent. Because of the number of tests conducted, the Bonferroni-Holm procedure was used to correct for possible Type I errors, yielding an error rate of .007.

Main effects of adolescent sex and ill parent sex have been previously reported; adolescent sex was associated with higher scores on ill parent reports of total problems and internalizing symptoms. No significant interactions were detected for models testing the RCMAS,  $F(1, 34) = .012$ ,  $p > .007$ ; RADS,  $F(1, 34) = .350$ ,  $p > .007$ ; or IES,  $F(1, 34) = .040$ ,  $p > .007$ ; CBCL Total Problems as reported by the ill parent,  $F(1, 33) = .229$ ,  $p > .007$ ; CBCL Total Problems as reported by the healthy parent,  $F(1, 31) = .091$ ,  $p > .007$ ; CBCL Internalizing Problems as reported by the ill parent,  $F(1, 33) = 1.161$ ,  $p > .007$ ; or CBCL Internalizing Problems as reported by the healthy parent,  $F(1, 31) = .053$ ,  $p > .007$ .

### Hypothesis 3: Adolescent Perceptions of Ill vs. Healthy Parent Communication

It was hypothesized that adolescents would perceive poorer communication quality with their ill parents compared to their healthy parents. This hypothesis was not supported. Means and standard deviations on the PACS are presented in Table 9 for the total sample as well as separately for boys and girls. A 2 (sex of adolescent)  $\times$  2 (health status of parent) repeated measures ANOVA was conducted on PACS scores to determine whether adolescents perceived poorer communication quality with their ill parent and whether this was affected by the sex of the adolescent. The main effect of parent health status was nonsignificant,  $F(1, 36) = 2.07$ ,  $p > .05$ . Results for the test of the main effect of adolescent sex were nonsignificant,  $F(1, 36) = 2.64$ ,  $p > .05$ . The

interaction effect between adolescent sex and health status of parent on communication scores was also nonsignificant,  $F(1, 36) = 2.21, p > .05$ .

Table 9

Means and standard deviations on Parent-Adolescent Communication Scale (PACS)

Parent group	Males (n = 13)		Females (n = 25)		Total (n = 38)	
	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>
Healthy parents	46.70	10.94	55.27	12.58	52.34	12.59
Ill parents	54.82	11.72	55.13	10.12	55.02	10.53
Mothers	51.99	10.97	58.15	10.56	56.04	10.96
Fathers	49.53	13.01	52.24	11.44	51.31	11.90
Same sex parents	49.53	13.01	58.15	10.56	55.20	12.02
Opposite sex parents	51.99	10.97	52.24	11.44	52.16	11.14

Note. Values represent T score conversions.

Secondary analyses were then conducted to assess for effects of other demographic variables on parent-adolescent communication. A 2 (sex of adolescent) x 2 (sex of parent) repeated measures ANOVA was conducted on PACS scores to evaluate whether adolescents reported differences in communication based on the sex of the parent or the match between adolescent sex and parent sex. Results for the main effect of adolescent sex were nonsignificant,  $F(1, 36) = 2.64, p > .05$ . The main effect of parent sex was nonsignificant,  $F(1, 36) = 2.30, p > .05$ . Finally, the interaction effect between adolescent sex and parent sex revealed no significant differences on the measure of communication,  $F(1, 36) = .39, p > .05$ .

Adolescent sex differences in communication were further examined using independent samples t-tests. The Bonferroni-Holm adjustment was used to control the error rate, requiring a significance level of .008 for the first (lowest) p-value. No significant differences emerged between girls and boys on ratings of perceived communication with mothers, fathers, ill parents, healthy parents, same sex parents, or opposite sex parents. In addition, PACS scores were not significantly associated with

adolescent age or the amount of time the adolescent had been aware of the parent's illness (see Table 8).

Finally, Welch's  $\chi^2$  tests were conducted on raw scores of the current sample compared to the normative sample collected by Olson (1985). Adolescents in the current sample rated communication with their mothers significantly better than did adolescents in the normative sample,  $\chi^2(9) = 3.09$ ,  $p < .05$ . No significant difference emerged for adolescent ratings of their fathers,  $\chi^2(7) = .55$ ,  $p > .05$ . Comparisons based on health status are not available as the measure has not been normed in this way.

#### Hypothesis 4: Relationship Between Parent-Adolescent Communication and Adjustment

Adolescent communication with the healthy parent was hypothesized to be a stronger predictor of adolescent adjustment than ill parent communication after testing for age, sex, perceived illness severity, and socially desirable responding. This hypothesis was partially supported. First, one-tailed bivariate correlation coefficients were calculated to examine the relationships between the subscales of the PACS, Problems in Family Communication (PFC) and Open Family Communication (OFC), and measures of adolescent adjustment (see Table 10). Because normative information based on parent sex is available only for total PACS scores, unadjusted raw scores were used during these initial correlations. Adjusted scores were used in regression analyses, reported next.

Perceived problems in the relationship with the healthy parent were significantly negatively correlated with RCMAS and IES scores, such that lower scores (more problems) were associated with more psychological symptoms. Open communication with the healthy parent as reported by adolescents was significantly negatively associated



with RCMAS scores and ill parent reports on the CBCL only. Total healthy parent raw scores were significantly associated with the RCMAS, IES, and ill parent CBCL scores.

Table 10

Correlations between measures of adjustment and PACS raw scores

Measure	Ill parent PACS			Healthy parent PACS		
	PFC	OFC	Total	PFC	OFC	Total
RCMAS	-.16	.06	-.06	-.38*	-.44*	-.48*
RADS	-.27	.01	-.15	-.25	-.10	-.20
IES- Total	-.01	.18	.10	-.41*	-.07	-.28*
CBCL Total- Ill	-.15	.10	-.03	-.23	-.37*	-.35*
CBCL Total- Healthy	.14	.12	.15	-.27	.00	-.17
CBCL Int.- Ill	-.18	.14	-.02	-.24	-.44*	-.40*
CBCL Int.- Healthy	.13	-.04	.05	-.06	.09	.01

Note. \*  $p < .05$ . All significance tests are one-tailed. PACS = Parent-Adolescent Communication Scale; PFC = Problems in Family Communication; OFC = Open Family Communication; RCMAS = Revised Children's Manifest Anxiety Scale; RADS = Reynolds Adolescent Depression Scale; IES = Impact of Event Scale; CBCL = Child Behavior Checklist; Int. = Internalizing

Adolescent descriptions of problems in their relationships with their ill parents were not significantly associated with scores on any adolescent adjustment measures. Similarly, open communication with the ill parent was not associated with any of the instruments assessing adolescent adjustment, nor were total raw scores for ill parent communication.

To determine whether adolescent reports of communication were more strongly correlated with adolescent adjustment, Williams tests for significant differences between dependent correlations were conducted using the PACS raw scores. Each dependent variable was treated as a family of tests, thus creating three tests for each variable. The Bonferroni-Holm procedure was used to adjust for the number of analyses conducted using one-tailed tests. Two comparisons were significantly different. The relationship between open parent communication and generalized anxiety symptoms was significantly



stronger for healthy parents than ill parents,  $t = 2.24$ ,  $p < .016$ . Also, the relationship between open parent communication and ill parent reports of internalizing symptoms was significantly stronger for healthy parents than ill parents,  $t = 2.64$ ,  $p < .016$ . For a complete list of these results, refer to Table 11.

Table 11

Differences between correlations of adjustment measures and PACS raw scores for ill and healthy parents

Measure	PFC		OFC		Total	
	$t$	$p$	$t$	$p$	$t$	$p$
RCMAS	1.06	.14	2.24*	.01	1.91	.03
RADS	.10	.46	.45	.33	.21	.42
IES- Total	1.97	.03	1.05	.15	1.64	.06
CBCL Total- Ill	.37	.36	2.07	.02	1.39	.09
CBCL Int.- Ill	.28	.39	2.64*	.01	1.68	.05
CBCL Total- Healthy	1.97	.03	.50	.31	1.36	.09
CBCL Int.- Healthy	.87	.19	.54	.30	.17	.44

Note. \* Significant difference. All significance tests are one-tailed. PACS = Parent-Adolescent Communication Scale; PFC = Problems in Family Communication; OFC = Open Family Communication; RCMAS = Revised Children's Manifest Anxiety Scale; RADS = Reynolds Adolescent Depression Scale; IES = Impact of Event Scale; CBCL = Child Behavior Checklist; Int. = Internalizing

To assess whether perceived communication with the healthy parent was a stronger predictor of adolescent adjustment than communication with the ill parent, regression analyses were performed using total PACS scores, adjusted for norms based on parent sex. An initial regression model was conducted, entering adolescent sex, adolescent age, perceived illness severity, social desirability, and whether the adolescent had experienced more than two stressors in the past year in a forward manner to determine their relevance to the primary regression model of interest. No correction for error rate was administered, as a more liberal approach to include any

potentially significant variables in the models of primary interest, those which examined the influences of parental communication, was desired.

No variables remained in the models of the RCMAS, RADS, or healthy parent CBCL Total Problems or Internalizing scores. The regression model for IES scores indicated that adolescent age was the only significant predictor in the model ( $R^2 = .13$ ),  $F(1, 36) = 5.49$ ,  $p < .05$ . The regression model for ill parent reports of Total Problems on the CBCL indicated that adolescent sex was the only significant predictor in the model ( $R^2 = .15$ ),  $F(1, 36) = 6.00$ ,  $p < .05$ . The model for ill parent reports of internalizing symptoms indicated that both adolescent sex (being male) and having experienced more than two stressors in the past year were significant predictors ( $R^2 = .32$ ),  $F(2, 36) = 7.84$ ,  $p < .05$ .

Next, regressions were conducted entering any significant demographic predictors, followed by adolescent reports of perceived communication with the ill parent (PACS T-scores), and, finally, by adolescent reports of perceived communication with the healthy parent. Forward selection and stepwise regression models yielded the same set of significant predictors; only the forward selection results will be reported. Using the seven adolescent adjustment measures as dependent variables, separate regression analyses were performed and the Bonferroni-Holm adjustment was used. The RCMAS model resulted in a significant predictive model ( $R^2 = .23$ ),  $F(1, 36) = 10.96$ ,  $p < .007$ . Higher healthy parent communication was associated with lower self-reported anxiety scores. No other models resulted in significant predictors at the established p-value.

### Hypothesis 5: Effects of the Presence of Positive Parental Relationships

It was hypothesized that adolescents with at least one positive parental relationship, as defined by the PACS, would have fewer reported symptoms of depression and anxiety than those with average or negative scores on the PACS. Scores one standard deviation or more above the mean were determined to represent positive communication in the parent-adolescent relationship. Adolescents were grouped according to how many parental relationships they had rated as significantly more positive than the normative sample: zero ( $n = 20$ ), one ( $n = 11$ ), or two ( $n = 7$ ). Initial  $t$ -tests were conducted to compare those adolescents who reported at least one positive parental relationship with those who had not. No significant differences were detected on adolescent self reports of anxiety on the RCMAS,  $t(36) = 1.519$ ,  $p > .007$ , depression on the RADS,  $t(36) = 1.184$ ,  $p > .007$ , or stress response symptoms on the IES,  $t(36) = -.165$ ,  $p > .007$ . Similarly, no differences emerged on descriptions of total problems in adolescent behavior by either ill parents,  $t(35) = 1.455$ ,  $p > .007$ , or healthy ones,  $t(33) = -.188$ ,  $p > .007$ , on the CBCL Total Problems scale. No significant differences emerged for descriptions of internalizing symptoms by ill parents,  $t(30) = 1.40$ ,  $p > .007$ , or healthy parents,  $t(33) = -.18$ ,  $p > .007$ .

Exploratory analyses were conducted to examine whether adolescents with two positive parental relationships appeared to fare better on measures of adjustment than those with one or no positive relationship. Comparisons indicated no significant differences between adolescents who rated communication with both parents as significantly better than average when compared to those who rated one or none of their parental relationships as positive (see Table 12).

Table 12

Means on measures of adjustment by number of positive parental relationships

Measure	0 (n = 20 <sup>a</sup> )	1 (n = 11 <sup>b</sup> )	2 (n = 7)
RCMAS, Total score	51.70	48.73	42.86
RADS, Total score	49.68	47.62	44.32
IES, Total score	27.50	30.00	25.57
CBCL, Ill parent, Total Problems	51.35	47.30	47.14
CBCL, Ill parent, Internalizing	50.40	46.00	46.00
CBCL, Healthy parent, Total Problems	48.78	50.20	48.43
CBCL, Healthy parent, Internalizing	48.33	48.30	49.86

Note. Values represent T score conversions, except for IES. <sup>a</sup>Sample size for CBCL, healthy parent = 18; <sup>b</sup>Sample size for CBCL, ill parent and CBCL, healthy parent = 10; RCMAS = Revised Children's Manifest Anxiety Scale; RADS = Reynolds Adolescent Depression Scale; IES = Impact of Event Scale; CBCL = Child Behavior Checklist

Hypothesis 6: Ill vs. Healthy Parent Reports of Adolescent Adjustment

It was hypothesized that healthy parents would endorse more problem behaviors than ill parents would report. To compare differences in the levels of symptoms endorsed by ill and healthy parents, dependent samples t-tests were conducted on the problem scale ratings of the CBCL. These tests indicated no significant differences on the Total Problems,  $t(33) = -.325$ ,  $p > .017$ ; Internalizing,  $t(33) = -.673$ ,  $p > .017$ ; or Externalizing scales,  $t(33) = .059$ ,  $p > .017$ .

Correlation coefficients were calculated to assess amount of parent agreement in symptom ratings. Significant correlation coefficients emerged between ill parent T scores and healthy parent T scores on both the Total Problems ( $r = .48$ ,  $p < .01$ ) and Externalizing ( $r = .54$ ,  $p < .01$ ) scales of the CBCL. On the Internalizing scale of the measure, healthy parent and ill parent ratings were not significantly associated ( $r = -.03$ ,  $p > .05$ ).

It was further hypothesized that healthy parent reports of symptomatology would be more strongly associated with adolescent reports of their own symptoms. While tests

indicated that no significant differences existed between the level of problems reported by healthy and ill parents, further examination of the data was performed to evaluate whether parental health status was related to the strength of association between parent reports on the full scales of the CBCL and adolescent self-reports on the RADS, RCMAS, and IES. Correlations between parent-report measures of adolescent adjustment and adolescent self-reports are presented in Table 13. Results indicated that ill parent reports of both Total Problems ( $r = .31, p < .05$ ) and Internalizing symptoms ( $r = .31, p < .05$ ) were associated with RCMAS scores in one-tailed significance tests. Ill parent reports of Total Problems were also correlated with RADS scores ( $r = .36, p < .05$ ). No other significant relationships emerged between ill parent descriptions of adolescent behavior problems and adolescent self-reports. Healthy parent reports were not significantly associated with adolescent reports of their emotional functioning.

Table 13

Correlations between measures of adjustment

Measure	1	2	3	4	5	6	7	8	9
1. RCMAS, Total	--	.60**	.16	.31*	.31*	.12	.24	.24	.17
2. RADS, Total		--	.11	.36*	.25	.26	.25	.10	.22
3. IES, Total			--	.12	.11	.05	.19	.18	.20
4. Ill- Total				--	.79**	.79**	.48**	.17	.47**
5. Ill- Int.					--	.38**	.17	-.03	.11
6. Ill- Ext.						--	.46**	.14	.54**
7. Healthy- Total							--	.84**	.86**
8. Healthy- Int.								--	.60**
9. Healthy- Ext.									--

Note. All significance tests are one-tailed. Variables 4 – 9 are Child Behavior Checklist (CBCL) scales. RCMAS = Revised Children's Manifest Anxiety Scale; RADS = Reynolds Adolescent Depression Scale; IES = Impact of Event Scale; Total = Total Problems scale; Int. = Internalizing Problems scale; Ext = Externalizing Problems scale

Because parent reports and adolescent reports were not strongly correlated, it was hypothesized that differences in the items forming the two measures may have yielded



differing reports of internalizing symptomatology. Therefore, measures were compared to identify items that were shared on both parent-report and adolescent-report questionnaires. These items are listed in Tables 14 and 15.

Table 14

Corresponding Items Used to Construct Matching Subset Between CBCL  
Anxious/Withdrawn Subscale and RADS

CBCL item	RADS item
12. Complains of loneliness.	3. I feel lonely.
14. Cries a lot.	8. I feel like crying.
33. Feels or complains that no one loves him/her.	12. I feel loved.
35. Feels worthless or inferior.	20. I feel I am no good.
103. Unhappy, sad, or depressed.	7. I feel sad.
112. Worries.	26. I feel worried.

Table 15

Corresponding Items Used to Construct Matching Subset Between CBCL  
Anxious/Withdrawn Subscale and RCMAS

CBCL item	RCMAS item
12. Complains of loneliness.	15. I feel alone even when there are people with me.
32. Feels he/she has to be perfect.	8. I get nervous when things do not go the right way for me.
34. Feels others are out to get him/her.	35. A lot of people are against me.
45. Nervous, highstrung, or tense.	34. I am nervous.
50. Too fearful or anxious.	7. I am afraid of a lot of things.
71. Self-conscious or easily embarrassed.	14. I worry about what other people think about me.
112. Worries.	6. I worry a lot of the time.

A “subset” score was generated for the RCMAS using only those seven items that matched symptoms described on the Anxious/ Depressed subscale of the parent-report CBCL. Similarly, only those seven items on the CBCL considered similar to the RCMAS items were used to generate a short-version score. The same procedure was used with six items on the RADS that were felt to match items on the CBCL Anxious/ Depressed subscale. Because of the nature of the items on the IES, few items



approximated those on the CBCL, therefore subset scores were not constructed for the measure. Reliability coefficients were in the moderate range and are reported in Table 16.

To determine whether adolescents and parents showed higher agreement when asked about the same internalizing symptoms, bivariate correlations were performed between adolescent subset scores for the RADS and RCMAS and healthy and ill parent subset scores for the corresponding CBCL items. One-tailed significance tests indicated that the correlation between the adolescent RADS subset and parent CBCL subset for corresponding items was nonsignificant for both ill ( $r = .19$ ,  $p > .05$ ) and healthy ( $r = .28$ ,  $p > .05$ ) parents. Similarly, the RCMAS subset was not significantly associated with subset scores of ill parents ( $r = .10$ ,  $p > .05$ ) or healthy parents ( $r = .25$ ,  $p > .05$ ).

Table 16

Reliability coefficients for parent and adolescent subset scores of RCMAS and RADS

Measure	RADS	RCMAS
Adolescent	.69	.75
Ill parent	.71	.63
Healthy parent	.65	.62

Note. RCMAS = Revised Children's Manifest Anxiety Scale; RADS = Reynolds Adolescent Depression Scale

## CHAPTER 6 DISCUSSION

### Discussion of Major Findings

#### Hypothesis 1: Adolescent Adjustment to Parental Physical Illness

The present study had the advantage of using multiple reporters to assess adolescent adjustment and emotional functioning in adolescents with severely chronically ill parents. For the most part, with regards to average symptom levels, adolescents', ill parents', and healthy parents' reports were in agreement that, overall, adolescents were in the subclinical range of scores on measures of internalizing and externalizing symptoms. While in contrast to the stated hypothesis, these findings are consistent with the majority of prior research in this area.

However, a larger proportion of adolescents were in the clinical range of scores on the measures of anxiety, the RCMAS and the IES, than on the depression measure, the RADS. This pattern of results contrasts previous work in this area, which has found more consistent findings related to depression than anxiety when comparing children of ill parents to those of healthy parents. These data may be attributable to differences between the sample used in this study and those of previous studies and support the hypothesis that for teens with severely ill parents, anxiety symptoms are more prominent than depressive ones.

First, parents in the study were severely ill and were receiving or considering invasive treatments for their diseases, of which their children were aware. In studies of

parents with diseases that typically require less dramatic treatments, such as HIV or chronic pain, children may have been less concerned about their parent's illness or less aware of the treatment regimen, and thus symptoms of anxiety may not have been as notable. It seems likely that children and adolescents, who presumably lack more sophisticated understandings of medical information to make decisions, may rely on external cues, like level of prescribed treatment, to make cognitive determinations regarding the level of seriousness of a parent's illness. With the current group of adolescents, their parents' needs for transplant, dialysis, or radiation may have served as evidence of the severity of their parents' conditions. This is supported by the fact that almost all of the adolescents reported that their parent's illness was moderately to extremely severe. It may be that in this group of adolescents, the perceptions of severe illness contributed to uncertainty about the future and, in turn, negative psychological consequences as suggested by Steele, Tripp, and colleagues (1997).

The age range of the children in the present study may have contributed to these findings as well. Most studies reviewed earlier included a broader age range that included younger children. It may be that adolescents, with greater cognitive development and abilities for abstract thinking, are more aware of the potential ramifications of their parent's health condition than are school age children. They may also be more likely to be provided with more information related to the parent's illness, thus contributing to worries as a result. The present sample, entirely composed of children more likely to be in this developmental range, may be at greater risk for experiencing anxiety as a result than a sample including younger children.

As noted earlier, the IES is a stressor-specific measure that examined anxiety in the form of intrusive thoughts and avoidance behaviors specifically related to the parent's health condition. The IES assesses symptoms distinct from those of generalized anxiety captured by the RCMAS. Unfortunately, IES normative data for a population similar to that in the present study was not available. However, the mean total IES scores for the current sample, while below the cutoff indicated by Neal et al. (1994), were comparable to scores reported in previous studies of children who had been exposed to traumatic events (see Table 2). These include children who had experienced a bus accident (Stallard & Law, 1993), a dormitory fire (Jones & Ribbe, 1991), and war (Kuterovac, Dyregrov, & Stuvland, 1994). In addition, several of the scores were similar to or higher than those reported for multiple life events in the sample of adolescents obtained by Joseph, Mynard, and Mayall (2000). Comparable to this study, these include adolescents who reported a history of life threat to a family member or friend through accident, injury, or illness. Other stressors rated similarly included life threat to self, experiencing a natural disaster, parental divorce, and parental substance abuse.

It is important to note that adolescent females' reports of symptoms on the IES in the study by Joseph, Mynard, and Mayall (2000) were significantly higher than males' reports on several events, including life threat to a family member or friend. This suggests that females may be more likely to report greater symptomatology in response to traumatic events. Given that the composition of the present sample was two-thirds female, the potential for somewhat elevated scores due to demographic characteristics was considered, as adolescent females appear to report more symptoms on the IES. However, examination of scores by sex indicated that this pattern was not present in the

current study; males reported slightly higher scores on the IES than females. This suggests that the experience of having a severely ill parent is distressing regardless of sex and can result in symptoms similar to those of children and adolescents who have experienced an acute trauma, such as an accident or disaster.

Adolescent age was moderately positively correlated with IES scores. Again, this may be a function of greater cognitive development that facilitated older adolescents' access to more troubling information provided by adults. This information, in combination with greater capacity to understand the possible ramifications of the illness, may have caused these higher scores. However, IES scores were the only adjustment measure significantly correlated with age. Reasons why this cognitive development would differentially affect scores on the IES and not more general measures of anxiety and depression are difficult to surmise. In addition, Compas et al. (1994), in using the IES with 6- to 30-year-old children of cancer patients, found the opposite pattern of results such that children had higher scores than adolescents, who had higher scores than young adults. Further research is needed to replicate this finding to determine the nature of the relationship between age and IES scores when used with children.

The scores on the IES are also noteworthy in that the comparison studies typically reported levels of symptoms within weeks of exposure to a traumatic event. Sixty percent of the adolescents in the present study had been aware of this stressor, their parent's illness, for more than one year. Two studies using the IES at multiple time points indicated that IES scores tend to decrease over time following acute exposure to trauma (Vila, Porche, & Mouren-Semeoni, 1999; Yule & Williams, 1990). In addition, findings from a two-year follow-up study of survivors of a coach accident (Curle &

Williams, 1996) indicated lower scores on the IES relative to other studies of children and adolescents who were victims of accidents when those studies were conducted more proximally to the time of the event.

Nonetheless, the findings for mean scores on the IES in this study remained comparable even after longer time since exposure to the information. In addition, measures of adjustment, including IES scores, were not associated with the amount of time that the adolescent had been aware of the diagnosis. It is also noteworthy that the scores in the present study were comparable to those studies measuring post-traumatic stress symptoms in adolescents experiencing ongoing stressors such as war (Kuterovac, Dyregrov, & Stuvland, 1994) or parental separation or divorce (Joseph, Mynard, & Mayall, 2000).

Terr (1991) has suggested a conceptualization of childhood trauma that includes mental harm inflicted by a single, unexpected event, referred to as a “type I” trauma, or by a chronic, repetitive series of events, defined as a “type II” trauma. Stress response symptoms have been most often studied following examples of “type I” traumas, such as natural disasters or transportation accidents, but less is known about these symptoms among those exposed to “type II” traumas, especially those in which the child is not the primary person experiencing the illness, but rather is a more secondary victim. For some adolescents, it appears that parental chronic illness may represent a “type II” trauma in which they experience traumatic reactions not in response to direct attacks on themselves, but rather indirect threats to their security through threats to their parents. Results from the IES in this study indicate that, even though adolescents do not directly experience the traumatic event (i.e., illness) per se, they do experience a stress response pattern similar



to children who do, such as direct victims of disasters. These symptoms appear to persist over time, as the stressor typically does not fade and remains via constant reminders of poor health status.

Given that nearly one-third of the present sample obtained scores at or beyond the recommended cutoff, it seems reasonable to conclude that a stress-response syndrome related to their parent's illness that interferes with daily functioning is a significant issue for many of these adolescents. It appears that the ongoing presence of parental illness can continue to elicit symptoms of avoidance and intrusion even after its initial presentation, causing distress similar to that typically associated with acute or extraordinary traumatic events. These results suggest that these effects are chronic and are likely grossly underestimated, contributing to distress among this population directly through their presence and indirectly through their effects on parent relationships. Symptoms of avoidance may have a profound impact on adolescents' relationships with ill parents if they avoid reminders of the illness and fragile health status that are likely associated with the parent's everyday existence. By not having social support from parents, the anxiety reactions described may be exacerbated further.

Interestingly, IES scores were not correlated with parent reports of adjustment. This suggests that, while parents may have some awareness of symptoms of depression and anxiety, they may have little knowledge of the intrusive cognitions and behavioral impact occurring for their adolescents. On the other hand, the IES may reflect a construct completely unassociated with the problems tapped on the CBCL, the parent-report measure used in this study. However, given the level of symptoms present on the IES in this sample, it seems unlikely that this would be completely unrelated to CBCL items.

This raises concern about the use of generalized measures of anxiety such as the RCMAS, which is more commonly used in clinical settings than the IES. This likely results in the underidentification of stress-response symptoms among children and adolescents even when chronic stressful life events are identified by clinicians. Broadly, these findings suggest that by widening the definition of “trauma” among adolescents and assessing for symptoms of a stress reaction, clinicians may be more likely to identify these difficulties and assist in their treatment.

Both healthy and ill parent reports indicated between nine and seventeen percent of adolescents in the clinical ranges on global measures of behavior problems (i.e. Total Problems, Internalizing, and Externalizing). However, despite numerous adolescents who reported clinical levels of anxiety on the RCMAS or IES, few parents reported clinically meaningful symptoms on the Anxious/ Depressed subscale of the CBCL despite several adolescents’ reports of significant anxiety symptoms on the RCMAS and IES. The CBCL lacks an anxiety subscale; rather it combines anxiety and depression into one subscale. It may be that CBCL items on this subscale reflect depressive symptoms more strongly than anxious ones, and therefore do not identify the concerns of these adolescents. The nature of internalizing symptoms may also have led to lower scores, as parents who are coping with multiple disease-related stressors may not be as attuned to their children’s emotional status.

Parent reports of adolescent functioning were relatively consistent between ill and health parents with regards to mean scores and percentages of teens in the clinical ranges. In the present study, the percentages of adolescents rated by parents as having significant levels of symptoms was consistently higher than the expected 2% of the sample. Of note,

ill and healthy parents reported 14 and 17% of adolescents, respectively, in the clinical range on externalizing problem behaviors. While externalizing behaviors were not the focus of the present study, this evidence suggests that a significant number of families observed behaviors of concern, warranting further investigation into acting out behaviors among adolescents with chronically ill parents. However, it should be noted that the number of participants in the present study was small and that each adolescent represented 2.6% of the sample.

Demographic characteristics were generally not associated with parent reports of adolescent functioning. However, ill parents described adolescent boys as having more total problems and exhibiting more signs of internalizing difficulties than ill parents of adolescent girls. The reasons for this difference are unclear, and findings related to communication do not illuminate this result. In addition, these results contrast those of Rotherham-Borus, Stein, and Lin (2001), who found that adolescent girls of parents with HIV reported higher levels of emotional distress while boys reported higher levels of behavior problems. The current sample showed no differences in externalizing behavior problems, which may be a function of the reporter (i.e., parent-report measure used in the present study).

Except where already noted, demographic factors, such as age and adolescent sex, were not associated with self-report measures of adolescent adjustment. The amount of time the adolescent had known about their parent's disease was not associated with adjustment. This result complements previous studies that have found no relationship between adjustment and length of diagnosis (Compas et al., 1994; Lewis et al., 1993) and

supports neither the hypothesis that the acute coping stages are most difficult or that longer time spent dealing with the stressor are associated with greater problems.

In addition, perceived illness severity was also not associated with any adjustment measures. This is in contrast to the findings from Compas and colleagues (1994), who found that perceived illness severity was associated with self-reports of IES symptoms although not generalized depression/anxiety symptoms. Several explanations for the current finding may exist. First, statistically, the range of responses describing illness severity was limited, with most of the adolescents indicating that their parent was severely ill. This restriction of range may have prevented detection of such an association. However, the scale used in this study was identical to that used in the Compas et al. (1994) research. Second, the range of objective illness severity, while not directly measured in this study, may have also been limited, as patients were selected because of their medical status. Finally, it may be that no such relationship exists and perceived illness severity is not associated with adolescent adjustment.

#### Hypothesis 2: Effects of Same Sex Ill Parents

The sex of the ill parent was not found to be associated with adolescent adjustment, as in some previous studies (e.g., Rodrigue & Houck, 2001). Also, unlike other studies in this area (Compas et al., 1994; Rodrigue & Houck, 2001) adolescents whose same sex parent was ill did not show evidence of greater adjustment problems than other adolescents. It may be that the severity of the illnesses in the present study made the sex of the parent less relevant from an emotional standpoint. However, the study by Compas and colleagues was conducted with families of patients with cancer, which is a

severe illness associated with high levels of uncertainty like those in the present study, making explanations for this finding somewhat unclear.

### Hypothesis 3: Adolescent Perceptions of Ill vs. Healthy Parent Communication

The effects of parental communication on adolescent adjustment in families in which one parent has a severe chronic illness was the focus of the present study, and several findings related to communication should be noted. First, no significant differences existed when comparing adolescents' communication ratings of ill parents to those of healthy parents. In contrast to the hypothesis that adolescents might have more access to healthy parents, feel less burdensome when disclosing information to them, and feel more comfortable asking questions, the total sample of adolescents did not report differences in communication based on the health status of the parent. The quality of parent-adolescent communication does not appear to have been affected by parental illness such that adolescents perceive significant differences in their relationships with their parents. This is positive information when considering factors affecting interpersonal dynamics for families with ill parents in that it suggests that adolescents do not feel more difficulties opening up to them versus healthy parents. It does not appear that the notion that ill parents might be perceived as emotionally unavailable or fragile is supported by these data.

Several reasons for this finding may exist. Ill parents may make special effort at effective communication with their children to compensate for other areas in which they may feel less able to participate. Adolescents may spend more time with healthy parents, which may allow for more openness for some and more conflict for others. Ill parents may avoid these conflicts to a larger extent because adolescents may feel less



comfortable arguing with them or because they are less available and choose to use time spent with their children in positive interactions. Another explanation for this finding may be that adolescents were reluctant to disclose negative feelings about their relationship with an ill parent. Guilt or shame may have led to socially desirable responses, thus inflating the scores. Supporting this hypothesis is the fact that the only adolescent-report measure of the study that significantly correlated with the social desirability index of the RCMAS was that assessing ill parent communication.

Previous research on parent-adolescent relationships has found that adolescents tend to perceive more openness (Barnes & Olson, 1985; Youniss & Smollar, 1985) and greater closeness (Paulson, Hill, & Holmbeck, 1991) with mothers than fathers but also tend to report more conflict with them as well (Montemayor & Hanson, 1985). While no significant differences emerged between mothers and fathers, it is noteworthy that the majority of healthy parents were mothers, making firm conclusions difficult to draw, as health status may partially account for results.

#### Hypothesis 4: Relationship Between Parent-Adolescent Communication and Adjustment

While no significant differences were reported in overall level of communication between ill and healthy parents, differences in their predictive qualities for adolescent adjustment did emerge. Adolescents' perceptions of communication with their healthy parents were significantly associated with their adjustment, while their relationships with ill parents showed less of a relationship. When the two subscales, openness and communication problems, were combined to form the total communication scale, communication with the healthy parent was related to generalized anxiety, stressor-specific anxiety, and ill parent reports of problem behaviors. The hypothesis that



relationships with healthy parents serve important and different roles with adolescents than those with ill parents in these families was also supported, as openness in the healthy parent relationship was significantly more strongly associated with lower generalized anxiety and lower reports of problems by the ill parent.

Specific aspects of communication also yielded somewhat different findings. When adolescents reported more problems in the relationship with their healthy parent, they also reported significantly more anxiety symptoms, both generalized and stressor-specific. Adolescents' descriptions of problems with their ill parents were generally not associated with their levels of psychological symptoms, although they were somewhat associated with depressive symptoms. Based on these results, it appears that conflict in the relationship with the healthy parent may be a significant risk factor for adjustment problems, especially anxiety symptoms. Increased conflict with a healthy parent may draw attention to difficulties in that relationship and cause adolescents to feel more dependent on the other parent, who may be viewed as medically fragile and unreliable for long-term support, thus causing anxiety about the future.

Similarly, adjustment problems were significantly associated with openness in healthy parent relationships but not in ill parent relationships. As hypothesized, it appears that more openness in relationships decreases the level of generalized anxiety that these adolescents experience. However, it was not associated with stress-response symptoms or symptoms of depression. Perhaps more openness is associated with greater sharing of information, which reduces uncertainty about the illness and thus reduces anxiety. The same effect might not be expected for traumatic reactions, where higher levels of ongoing information might be hypothesized to increase avoidance and intrusive

thoughts, or depression, where openness may not relieve negative feelings about the self, the world, and the future that have been theorized to cause depression (Beck, 1967).

Nonetheless, the regression analyses used to examine the predictive ability of parent-adolescent communication yielded differing findings. Only better perceptions of communication (i.e., more openness and less conflict) with the healthy parent predicted lower levels of generalized anxiety symptoms on the RCMAS. This result supported the underlying premise that adolescents who perceived a positive relationship with their healthy parent would rely on that relationship over that with an ill parent for information that might reduce anxiety symptoms. It may also be that adolescents with positive relationships with their healthy parents experienced a greater sense of general life security that reduced feelings anxiety even with the potential threat of the loss of a parent.

Depressive symptoms, on the other hand, were not significantly predicted by any variables entered into the model. As noted earlier, this suggests that reactions of depressive symptoms may be less amenable to change via qualities of a positive communication relationship provided by a parent. These may include information, support, and openness, and it suggests that other variables in these adolescents' lives are stronger predictors of depression than parent-adolescent relationships.

Unlike generalized anxiety symptoms, stress-response symptoms of anxiety were not predicted by parent-adolescent communication with either parent in the regression models. Higher scores on the IES were associated with older adolescent age only. As discussed earlier, this may be related to greater cognitive development and increased understanding of the potential impact of parental illness on their lives. It may also be that the nature of these anxiety symptoms, associated with Post-Traumatic Stress Disorder, is

reactive and not able to be affected by social support in the form of parental communication. These symptoms may, in fact, be exacerbated for some adolescents with open relationships with their parents if those parents discuss illness-related information that adolescents are attempting to avoid or causing distress in the form of intrusions.

Regression analyses did not support the hypothesis that adolescent perceptions of communication with their healthy parents would predict level of adjustment as reported by their parents. Demographic variables, while not significantly predictive, were moderately influential and may represent factors that are more strongly considered by parents when interpreting adolescent behavior.

Results for the regression models yielded fewer significant predictive relationships than the correlation analyses conducted on the PACS subscales. This may have occurred for several reasons. Due to the amount of power associated with the sample size, few variables could be entered into the regression models. Therefore, rather than entering the PACS subscales and the total communication scores for both parents, only total scores were used. It appears that the specific aspects of communication, openness and conflict, may contribute differently to adolescent adjustment and may not have been adequately reflected in the total communication scores. Also, standardization of scores based on sex of parent was available only for total communication scores. While the correlation analyses were conducted on absolute levels of openness and problems, regression analyses were performed on scores adjusted based on normative information. This standardization may have affected the statistical outcomes. Finally, the correlation analyses were bivariate and did not include other variables, while regression analyses did. Changes in results occurred most notably for symptoms of

stress-response and ill parent reports of behavior problems, both of which were moderately predicted by demographic variables as well. It may be that variance associated with these scores was better accounted for by these variables than by parent-adolescent communication, and thus its significance in prediction was lessened.

#### Hypothesis 5: Effects of the Presence of Positive Parental Relationships

It was hypothesized that adolescents who described at least one parental relationship, regardless of which one, as significantly more positive than the norm would report better adjustment than those who did not have an especially good relationship with either parent. This was not supported by the data and does not support the effect noted in Forehand, Middleton, and Long (1987). However, this finding was with adolescents of presumably generally healthy parents undergoing divorce. It may be that adolescents do not benefit as much from the strength of a single parental relationship, as previously identified, if that relationship is with a seriously ill parent, and they feel a threat of losing that parent to significant illness.

The fact that effects on adjustment were not noted for mere presence of a positive relationship but were noted in regression analyses based on the health status of the parent supports this idea. It may be that adolescents perceive some insecurity in their relationship with their ill parent, whether that relationship is good or bad, and that developing a close relationship to a parent who may become unavailable somewhat reduces the positive impact of having that close relationship. More knowledge related to adolescents' perceptions of ill parents is necessary to answer these assertions.

### Hypothesis 6: Ill vs. Healthy Parent Reports of Adolescent Adjustment

The final area of interest in the present study was examining the impact of health status on the reports of parents, as this may be relevant to the interpretation of findings throughout the literature. Specifically, it was hypothesized that ill parents may be less attuned to their children's emotional functioning because of the demands that chronic illness places on them. To test this hypothesis, analyses were conducted to examine differences and similarities between ill parents' descriptions of their adolescents and those of healthy parents and adolescents themselves. Healthy parents and ill parents did not differ significantly in the extent of the problems they described among their children. This may be a function of the marital relationships of those who participated in the study and reflect communication between partners about their adolescent children such that ill parents were kept abreast of behavioral issues. It may also simply argue against the notion that ill parents have less awareness than healthy ones regarding their children's functioning. The impact of illness, even with severely chronically ill patients, may take a backseat to the monitoring of their children's well being.

Indeed, parent reports of adolescent behavioral symptoms on the CBCL were moderately and significantly correlated for total problems and externalizing behavior. However, their reports were not associated on descriptions of internalizing behavior. This likely has little to do with the health status of parents in the study and is consistent with the nature of the behaviors reported. Externalizing behaviors tend to be more objectively observable than internalizing ones and thus lead to greater interrater agreement.



In contrast to hypotheses, it was not healthy parents whose reports of adolescent behavior problems were significantly associated with the adolescents' reports of emotional distress, but rather those of ill parents. However, these were moderate correlations, and the CBCL examines a broader range of behavior than the measures administered to the adolescents. Therefore, responses to specific symptoms were extracted from the measures to examine the degree to which parents agreed with the level of internalizing symptoms reported by their adolescents. The nonsignificant findings that resulted from this approach may be a result of the fact that these subsets omitted key symptoms, thus not truly representing the emotional pattern in question.

Nonetheless, the fact that agreement on these symptoms was not significant is meaningful, though not particularly surprising. Overall in the present study, teenagers and parents showed only low to modest agreement on specific symptoms of adolescent anxiety and depression, consistent with other research findings (Achenbach, McConaughy, & Howell, 1987; Engel, Rodrigue, & Geffken, 1994; Hartos & Power, 2000; Stanger & Lewis, 1993).

Taken together, results suggest that health status is not relevant to perceptions of children's emotional functioning and that being healthy does not play a role in factors that might give them insight into their children's well being and conversely, and perhaps more importantly, being ill does not lead to particularly poor insight into their adolescent's functioning beyond what is typical. Therefore, the issues related to reporter biases in this literature do not appear to be of major concern.



### Summary of Findings

Taken together the present study allows several major conclusions. First, average levels of adjustment on measures of the traditional psychological constructs of depression and generalized anxiety do not appear to be significantly higher among these adolescents than the general population, although several had clinically significant difficulties in these areas. Stress-response symptoms, however, appear to be much more prevalent among adolescents of chronically ill parents and are likely overlooked.

Second, for the most part, other demographic factors explored here were not associated with adjustment among these adolescents. These included age, sex, time since knowledge of diagnosis, sex of parent, and concurrent stressors.

Third, findings related to the predictive utility of parent-adolescent communication to adolescent adjustment suggest that the relationship with the healthy parent serves important and unique functions in comparison to the ill parent relationship, particularly with regard to anxiety symptoms, but some inconsistencies exist in the patterns of findings. Further research will be useful in elucidating these results and guiding clinical interventions.

Finally, evidence presented here does not provide adequate support for the assumption that biases exist in the reporting of adolescent behavior problems by ill parents in comparison to healthy ones on descriptions of internalizing behaviors. While healthy parents' reports of specific internalizing symptoms were somewhat more strongly correlated with adolescents' self-reports, these correlations were moderate at best and do not indicate that they are in greater sync with their adolescents than ill parents.

### Contributions and Weaknesses of the Present Study

In addition to the empirical findings described, the present study contributes to the literature through several unique methodological and conceptual features that enhance its significance. First, the present study addressed methodological issues that previously have been cited as problems. It included both ill mothers and ill fathers in the same sample, thus allowing comparisons that are rare in a literature dominated by research groups using sex-linked diseases (e.g., breast cancer, hemophilia). Second, assessments were obtained from the patient, the healthy parent, and the adolescent. Multiple raters allowed for analyses not previously reported, such as those related to reporter biases. Third, this study increased generalizability of the findings by using a sample of patients with various illnesses, including kidney disease, liver disease, cancer, and heart disease. This type of heterogeneous sample, virtually unheard of in this literature, allows for interpretation regarding the effects of severe parental illness as a stressor rather than the effects of a specific disease. Finally, both ill parent and healthy parent communication were included in the same regression models for prediction of adjustment. Previously, the simultaneous inclusion of the relationships with both parents had not been conducted.

The study makes conceptual contributions to the literature as well. In his review of the state of research addressing parental health and child outcomes, Drotar (1994) noted two important concepts to consider: compensatory factors (e.g., parent-adolescent relationships) and developmental influences (e.g., adolescence). The focus of this study was the examination of the potentially beneficial effects of positive parent-adolescent communication. It is conceptually and methodologically unique by its inclusion of both parents in the model simultaneously. It was hoped that by better understanding the

relative importance each parent plays in such families, clinical work might address family relationships as they affect adolescents adjusting to the significant illness of a parent.

Another conceptual strength is the study's examination of an age group that may be specifically at risk, adolescents. Most of the studies reviewed used a wide age range that included adolescents. Some examined age differences, noted earlier, but many did not, despite recognized developmental differences in children's reactions to parental illness (Patenaude, 2000). Therefore, our current knowledge of this population is limited by studies paying little attention to development in children's responses to stress, coping abilities, and societal expectations. Even within the age range examined here, ages 12 to 17, it was necessary to examine age differences, as important developmental changes occur throughout this time frame. However, by maintaining a focus on this age group believed to experience the greatest distress in reaction to this event, it was hoped that our knowledge of mechanisms that may alleviate this distress might increase.

Indeed, the potential clinical implications of this research are noteworthy. Christ et al. (1994) used interventions aimed at improving parent-adolescent relationships in families with a terminally ill parent, and their qualitative reports suggest that this was helpful for many families. The current study aimed to test the utility of employing such recommendations with non-terminally ill families, specifically by examining whether emphasizing the healthy parent-adolescent relationship would provide a more specific, useful recommendation for clinicians working with families in which one of the parents has an illness. While the results provide only limited support for this position, they represent an important and significant first step for an ever-growing population of young people.

Perhaps one of the most important contributions of this study is its consideration of the concept of illness as a stressor, rather than the examination of one particular disease and its effects on the family. Nearly all of the existing studies focus on three disease types: cancer, HIV/AIDS, and chronic pain. The need for comparisons of different illnesses has been raised as a criticism of this field (Armistead et al., 1995), yet this remains virtually unexamined in the literature. Admittedly, different health conditions vary on several dimensions, making comparisons somewhat difficult. Rolland (1987) has proposed a psychosocial typology of chronic illness considering the onset of the illness, nature and extent of disability, course of the illness, and prognosis. These factors can create different stressors for adolescents and their families, and these are important to study. However, if the term “illness” is to be used throughout this literature as a causal mechanism affecting children, studies using heterogeneous parent populations continue to be necessary. Those studies will enable us to understand the general impact of illness in the family and not simply the specific stressors of a given disease. For example, Biggar and Forehand (1998) noted that HIV studies are not generalizable to other disease types because of the unique circumstances, such as social stigma, associated with the condition.

The final conceptual contribution of this study to the literature is its consideration of the parent-adolescent relationship on a basis of more than just conflict. Most of the studies reviewed used psychometric measures of parent-adolescent conflict as their conceptualization of the parent-adolescent relationship. While this is one important aspect of this dyadic relationship, as noted earlier, different patterns of adjustment appear to be related to the different aspects of parent-adolescent functioning. Thus the

conclusion that parent-adolescent communication is another critical feature of this relationship appears warranted. For reasons described earlier, communication may be especially critical in families facing both acute and chronic stressors associated with parental illness, and this variable may account for successful adjustment in adolescents.

However, several weaknesses in the study should also be noted. First, problems with the sample exist. The sample size may not have been large enough to detect some significant effects. In addition, it was not evenly distributed; the majority of adolescents were female and the majority of ill parents were fathers, making the majority of healthy parents mothers. These differences, while not dramatic, suggest that some of the interpretations of the data should be made with caution. Effects of ill parents could also be influenced by the fact that these parents were more likely to be male.

Measurement tools may also have been insensitive to issues relevant to the present sample. First, while the CBCL is a useful screening instrument, it may not have been sensitive to the symptoms of depression and anxiety that were of interest in the present study. Indeed, the CBCL combines these two psychological constructs into one subscale, decreasing the ability to separate parent reports of the two forms of emotional distress. This combined scale also had poor statistical properties with the present sample, preventing its use in most analyses. It may be that other parent-report measures with more detailed examination of internalizing behaviors, such as the Behavioral Assessment System for Children (BASC; Reynolds & Kamphaus, 1992), may have been more useful for obtaining parent opinions of their children's functioning.

The measure of adolescents' perceptions of the severity of their parents' illness also may not have been sensitive to differences in adolescent perceptions. The scale



included only five points, of which the majority of adolescents chose only the top three choices. It may be that the measure was not sensitive to differences in the way the current sample perceived their parents' illnesses.

Third, the role of social desirability in adolescent responses is somewhat difficult to determine. Only four (11%) of the adolescents in the present sample responded at the 90<sup>th</sup> percentile or above on the RCMAS Lie scale, indicating that most adolescents were forthcoming in completing measures. The only comparable data available for such a population found that in a sample of children ages six to ten, 35% responded at this level on the RCMAS Lie scale, considerably higher than the present sample. Causing caution nonetheless is the finding that Lie scale scores were significantly positively correlated with adolescent descriptions of their relationships with their ill parents. This creates some question about whether responses on this measure were artificially inflated when responding about the ill parent. It may be that some adolescents felt it was inappropriate to criticize their relationship with an ill parent and instead chose to emphasize the positive aspects of their relationship. If this occurred, it may cast some doubt whether the conclusions drawn here regarding the relatively limited impact of ill parent communication on adjustment represents an overestimation of its relevance.

Another weakness is the common practice, employed again here, of equating all "other" stressors when considering concurrent life stresses for these adolescents. While this is not an ideal practice, any consideration of other ongoing stressors represents an improvement to this literature, as only one previous study, has examined this contribution to functioning (Hirsch, Moos, & Reischl, 1985). The fact that the presence of two additional stressors in these adolescents' lives was not associated with differences in



adjustment is different than results from some of the general adolescent stress literature. This may indicate that adolescents with chronically ill parents face numerous stressful challenges directly related to their parent's health status, such as increased home responsibilities, in addition to the concern for their parent's health. In addition, Hirsch, Moos, and Reischl's (1985) have suggested that adolescents with chronically ill parents may be particularly sensitive to any life events that occur to them. Consistent with this, perhaps this is not a significant variable because these adolescents are already vulnerable by virtue of the "one" stressor of having a severely ill parent.

Despite its weaknesses, the present study can serve as a springboard for future research in this area. Priorities for future research should include other risk factors that were not examined in this study that may significantly contribute to parent-adolescent relationships. Specifically, parental depression or marital strain can have an impact on all family relationships and may contribute to communication patterns as well as the psychological functioning of other family members. The interactions of these variables with parent-adolescent communication and their effects on adolescent functioning will be critical to elaborating our understanding of risk and protective factors for this potentially vulnerable population.

The current study examined a specific area of adolescent communication, that with their parents. However, the impact of other relationships was not explored and provides an important area to consider. Adolescents' use of extended family, peers, or other significant adults in coping with this ongoing stressor is an area of study that may help to explain variance in their adjustment to this stressor.

The present study did not directly consider adolescent coping responses, although evidence emerged suggesting that some adolescents responded with behaviors resembling avoidant coping strategies, which has been associated with internalizing symptoms (Compas et al., 1994). However, little empirical work exists regarding the coping strategies of children in this potentially chronically stressful situation, and this should be a focus of future studies. In addition, the interaction between adolescent coping and parent-adolescent communication has important implications for understanding the experience of having a chronically ill parent and should be further investigated.

Future research would also benefit from expanding the scope of inquiry on the impact that parental illness can have on adolescent adjustment by examining this and other areas of adolescent functioning, such as substance use and school achievement. Rather than relying solely on more traditional measures of psychological adjustment, other outcomes should be examined in light of the findings from this study indicating that many of these adolescents reported behavioral avoidance of illness reminders and experienced intrusive thoughts related to it. One form of an avoidant coping response is substance use, which was not assessed in the present study and may be a relevant issue for this population. Academic achievement is another outcome that warrants examination, as the impact of intrusive thoughts may have an effect on learning and school performance. As shown by the present study with its use of the IES, the inclusion of nontraditional outcome measures can enhance the understanding of at-risk populations in unpredicted ways.

Finally, the majority of research, like this study, has used cross-sectional, descriptive designs. Other methods are needed to explore the impact of having a

chronically ill parent. Of particular benefit would be research longitudinally tracking the health status of parents, beginning when they are healthy. This design would allow for baseline assessments of child adjustment prior to the diagnosis of parental health conditions, providing for comparisons of functioning before diagnosis, after diagnosis, over time, and over changing health status. In addition to longitudinal research, intervention studies are needed to investigate ways to improve the lives of these adolescents. Rotherham-Borus and colleagues (Rotherham-Borus, Lee, Gwadz, & Draimin, 2001; Rotherham-Borus, Stein, & Lin, 2001) have begun interventions with adolescents of parents with HIV/AIDS, a valuable and unique contribution to this area which has made evident the need for more work in this area.

Clearly, the understanding of adjustment during adolescence is a complex undertaking. The consideration of additional variables and attempts at longitudinal and intervention studies in this population with extra stressors must be included in future research programs to move forward this critical research area.

## APPENDIX

**Thank you for agreeing to participate in this study. Please answer the following questions about your family as completely as possible. Throughout the questionnaire, “adolescent” refers to \_\_\_\_\_.**

### **FAMILY INFORMATION**

Please list all persons in your family who currently live at home with you:

Name	Sex	Age
_____	_____	_____
_____	_____	_____
_____	_____	_____

Home address: \_\_\_\_\_

\_\_\_\_\_

Phone number: \_\_\_\_\_

What is your family's estimated total yearly income? (This information is used for descriptive purposes only)

_____ less than \$10,000	_____ \$20,000-29,999	_____ \$40,000- 49,999
_____ \$10,000- \$19,999	_____ \$30,000- 39,999	_____ \$50,000 or more

### **PATIENT INFORMATION**

Date of birth: \_\_\_\_\_

Highest grade completed in school: \_\_\_\_\_

Current occupation: \_\_\_\_\_

Medical diagnosis: \_\_\_\_\_

Date of diagnosis (month and year): \_\_\_\_\_

When did your child first learn that you had a chronic illness (month and year)? \_\_\_\_\_

Number of hospitalizations for current illness: \_\_\_\_\_

If you are being or have been evaluated for a solid organ or bone marrow transplant, please complete the items in this box. If not, please skip them.

When was transplantation first mentioned as a possible treatment (month and year)? \_\_\_\_\_

When was the decision to pursue transplantation made (month and year)? \_\_\_\_\_

Is your adolescent aware that you are being or have recently been evaluated as a transplant candidate? **YES NO**

If so, when did you first discuss this decision with your adolescent (month and year)? \_\_\_\_\_

What is your relationship to the adolescent? Please be as specific as possible, for example, "step-mother," "biological father" or "live-in partner of biological mother."

## PARTNER INFORMATION

Date of birth: \_\_\_\_\_

Highest grade completed in school: \_\_\_\_\_

Current occupation: \_\_\_\_\_

What is your partner's relationship to the adolescent? Please be as specific as possible, for example, "step-mother," "biological father" or "live-in partner of biological mother."

## ADOLESCENT INFORMATION

Name: \_\_\_\_\_ Sex: \_\_\_\_\_

Date of birth: \_\_\_\_\_ Grade in school: \_\_\_\_\_

Ethnicity: \_\_\_\_\_ White \_\_\_\_\_ Black \_\_\_\_\_ Hispanic \_\_\_\_\_ Asian-American  
 \_\_\_\_\_ Native American \_\_\_\_\_ Other \_\_\_\_\_

Please indicate whether your adolescent has experienced any of the following events in the past year.

\_\_\_\_\_ Death of a friend \_\_\_\_\_ Change in residence \_\_\_\_\_ Legal problems  
 \_\_\_\_\_ Death of a relative \_\_\_\_\_ Family financial problems \_\_\_\_\_ Parental divorce  
 \_\_\_\_\_ Academic problems \_\_\_\_\_ School change \_\_\_\_\_ Parental remarriage

Best time to call to reach adolescent at home (day and time): \_\_\_\_\_

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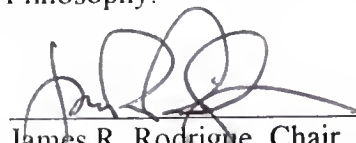
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## BIOGRAPHICAL SKETCH


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I certify that I have read this study and that in my opinion it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a dissertation for the degree of Doctor of Philosophy.



James R. Rodrigue, Chair  
Professor of Clinical and Health  
Psychology

I certify that I have read this study and that in my opinion it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a dissertation for the degree of Doctor of Philosophy.



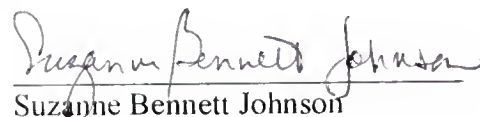
Stephen R. Boggs  
Associate Professor of Clinical and  
Health Psychology

I certify that I have read this study and that in my opinion it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a dissertation for the degree of Doctor of Philosophy.



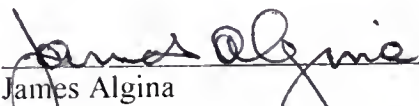
James H. Johnson  
Professor of Clinical and Health  
Psychology

I certify that I have read this study and that in my opinion it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a dissertation for the degree of Doctor of Philosophy.



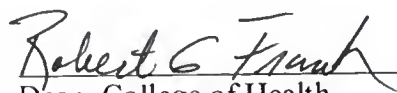
Suzanne Bennett Johnson  
Distinguished Professor of Clinical  
and Health Psychology

I certify that I have read this study and that in my opinion it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a dissertation for the degree of Doctor of Philosophy.

  
James Algina  
Professor of Educational  
Psychology

This dissertation was submitted to the Graduate Faculty of the College of Health Professions and to the Graduate School and was accepted as partial fulfillment of the requirements for the degree of Doctor of Philosophy.

August 2002

  
Dean, College of Health  
Professions

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Dean, Graduate School

